A STUDY OF SOME OF THE PSYCHOLOGICAL ISSUES AFFECTING WOMEN UNDERGOING TREATMENT FOR URINARY INCONTINENCE

by

KATHARINE HILARY LOANE

A thesis submitted to
The University of Birmingham
For the degree of
DOCTORATE OF MEDICINE

School of Health and Population Science
The University of Birmingham
2010

ABSTRACT

Title A study of some of the psychological issues affecting women undergoing treatment for urinary incontinence.

Background There is evidence suggesting that effective clinical treatment of urinary incontinence (UI) is not reflected in patients' quality of life reports or in psychological well-being. There may be other psychological issues that are not routinely captured but may be influential in recovery.

Aims and objectives To explore women's experiences of UI and identify what aspects are not altered by stress incontinence (SUI) surgery, to identify themes with which to develop a treatment-planning tool and to identify measures to improve patient satisfaction.

Methods Qualitative interviews and repertory grids were performed on women with UI. Themes generated from these women, together with themes from a literature review and a focus group, form the basis for future questionnaire development. Data were scrutinised for additional potential to improve satisfaction.

Results Wide-ranging themes were identified. Psychosocial aspects are not fully addressed by traditional UI treatment. Many suggestions for improvements in management were identified.

Conclusions There is much that can be done to try to improve satisfaction for women with UI. Many themes have been identified as a basis for the further development of a treatment-planning tool.

DEDICATION

To Marcus, Mum and Dad.

ACKNOWLEDGEMENTS

I acknowledge both my supervisors Phil Toozs-Hobson and Carolyn Hicks for inspiration and guidance from planning to completion and Kim and Kal, the hardworking continence nurses for their support and patient recruitment.

I am grateful to all the women who took part in this study, without whom this work would not have been possible.

Thanks to Mervyn Robb and Hilary Robb for proof reading.

Funding for the researcher's salary was from the Urogynaecology research fund, Birmingham Women's Hospital. A prize from the Jo Jordan Scholarship contributed to conference attendance and presentation of preliminary data as did the Urogynaecology research fund.

TABLE OF CONTENTS

LIST OF ILLUSTRATIONS

LIST OF TABLES

ABBREVIATIONS

BDI	Beck depression inventory
BSI	Brief symptom inventory
CCEI	Crown Crisp experiential index
CINHL	Cumulative index to nursing and allied health literature
CBT	Cognitive behavioural therapy
COREC	Central office for research ethics committees
CRD	Centre for reviews and dissemination
CUI	Coping with urinary incontinence
DOH	Department of Health
e.g.	for example
EPI	Eysenck Personality Inventory
EBM	Evidence based medicine
GP	General Practitioner
HADS	Hospital anxiety and depression scale
HRT	Hormone replacement therapy
ICP	Integrated care pathway
ICS	International Continence Society
IIQ	Incontinence impact questionnaire
ISC	Intermittent self catheterisation
KHQ	Kings health questionnaire
LREC	Local research ethics committee
MMPI	Minnesota multiphasic personality inventory
MUI	Mixed urinary incontinence

NCHOD	National Centre for Health Outcomes Development
NHS	National Health Service
OAB	Overactive bladder
PALS	Patient advocate liaison service
PCP	Personal construct psychology
PCT	Personal construct theory
PFMT	Pelvic floor muscle training
PSCAN	Psychological screen for cancer
PSM	Psychological stress measure
QoL	Quality of life
RCT	Randomised controlled trial
RIFT	Range of impaired functioning tool
SDI	Social difficulties inventory
SDSRI	Sabbatsberg depression self-rating index
STAXI	Stait trait anxiety inventory
SUI	Stress urinary incontinence
TOT	Transobturator tape
TVT	Tensionfree vaginal tape
UDI	Urogenital distress inventory
UDO	Urodynamic detrusor overactivity
UI	Urinary incontinence
UK	United Kingdom
USI	Urodynamic stress incontinence
UTI	Urinary tract infection

UUI	Urgency urinary incontinence
VAS	Visual analogue scale
WHI	Women’s Health Initiative
YIPS	York incontinence perception scale

CHAPTER 1

OVERVIEW

1.1 Background

Successful treatment of urinary incontinence (UI) in women does not seem to match with quality of life (QoL) and self reported satisfaction among women with UI. This may be because the standard measures and clinical consultations are not capturing the full range of issues. One reason for this may be the nature of the problems, which for social desirability reasons, women wish to keep hidden; this would indicate the need for a more opaque measure. It may also be the case that the QoL tools lack construct validity, meaning that the measures will only assess what the test developer considers to be important, as opposed to covering the full range of core issues. Alternatively it may be that something more psychologically fundamental is going on in that the QoL tools are capturing the right data, but that no amount of clinical success will rectify patient dissatisfaction, social phobias or whatever else may be creating dissatisfaction.

This study was concerned to establish what is reported in the literature and with regard to standard measures (e.g. QoL) and what women self report under open

investigation (i.e. focus group and interview) and what they report via opaque investigations (i.e. repertory grids). By doing this, some additional factors may be revealed that are germane to the dissatisfaction felt by some women post successful surgery.

It may benefit patients to formulate customised care plans rather than adopting a 'one size fits all' approach. In order to do this it is necessary to have a way to capture all the factors needing to be addressed for each patient. There is no such treatment-planning tool available and this is the first phase of the development of such a tool.

1.2 The research question

Are there factors not currently addressed by current continence treatment that could be limiting patient satisfaction? This project aims to identify a range of psychological factors in women who experience dissatisfaction. There will be a study of women with UI in general and in addition a focus on those with stress urinary incontinence (SUI) to find out what aspects are left untreated or unresolved by current treatments.
The aim is not necessarily to find common factors as the study focuses on individuals. The primary methodology (the repertory grid) is used to identify individual factors. Psychological factors may inform treatment but if they are not covered by existing QoL measures, then alternative psychometric measures would need to be developed as well. If the measuring tools are not measuring what they should be measuring then they will provide misleading information, leading to wasteful and ineffective treatment and management.

1.3 The research plan

- To perform a literature search to find out what women's experiences are of UI
- To perform a literature search to find out what is known about the association between urinary problems and psychological problems and to find out what is known about the effectiveness of psychological interventions for patients suffering urinary incontinence (UI)
- To extract themes from a continence focus group to increase the knowledge base of the experience of UI and its management
- To conduct a pilot series of interviews and repertory grids with women with UI to refine the technique for conducting interviews and repertory grids
- To conduct interviews and repertory grids with two groups of women with the aim of exploring their experiences of UI and it's treatments (see Table 1.1)
- To identify a third group of women due to undergo stress incontinence surgery and apply measures preoperatively and postoperatively (see Table 1.1) and to study each case to determine each patient's expectations of continence surgery
- To compare the postoperative interview with the preoperative interview for each case study from group 3 to identify factors impairing patient satisfaction
- To identify themes with which to develop a screening tool to apply to incontinent patients to determine whether they need additional psychological support or educational measures and to predict whether or not they are likely to benefit from different incontinence treatments. The themes are generated by thematic analysis of the literature, focus group, interviews and repertory grids

- To revisit the literature review, focus group and interviews and compile suggestions for future improvements relating directly to comments and suggestions made

Table 1.1 Study groups

Group	Aim	Subjects	Methodology	Analysis	Outcome measures
1	To gather information on experience of UI and its management	20 women currently using the hospital continence service	Repertory grids. Qualitative interview	Thematic analysis of bipolar constructs from grids. Thematic analysis of interview text	Themes
2	To gather information on UI and it's treatments with an emphasis on surgery	20 women who have had a previous stress incontinence operation at any time	Repertory grids Qualitative interviews	Thematic analysis of the bipolar constructs from the grids. Thematic analysis of interview text	Themes

3	To examine why women who are cured of UI may still be dissatisfied	14 women awaiting stress incontinence surgery who had surgery and attended for a postoperative assessment	Preoperatively: Repertory grids, interview, situations affected by UI and pad use questionnaire, KHQ and urodynamics. Postoperatively: the same as preoperatively plus a VAS regarding subjective success of surgery	Case study of each case to identify factors not addressed by treatment. Interpretation of grids to identify hopes, expectations and realities of surgery	Factors of dissatisfaction

1.4 The overall significance of this study

This study is aimed at improving the overall management of women with UI. Previous work has focused on improving objective measures of cure. There has also been work looking at quality of life and how this is affected by treatments. Research in this area has typically focused on a before/after approach to assess the impact of various forms of treatment. None of the work done prior to this study uses any of these

factors to actually plan treatment. This work is an exploratory piece of work drawing various aspects together but starting without assumptions of what is important to women with UI. By examining these women using methods that avoid presumptions (repertory grids and qualitative interviews) it is anticipated that this work will examine women's experience of UI and its treatments in a way that has not been done before. The insight provided by the subjects in this study will help clinicians to better understand their patients' experience of UI and its management. This is more likely to result in satisfaction and is therefore highly significant. The results from this study will be used as building blocks for further work to develop a treatment-planning tool that will help develop more appropriate management plans for patients with UI. This should lead to increased patient satisfaction and reduce poor compliance and wastage of health resources not leading to benefit.

QoL measures are often conducted in this area and when clinical interventions are not successful in ameliorating patients' QoL this may result in costly follow-up, subsequent treatments and support. The mismatch between clinical outcome and QoL, however, may be a function of poor measuring tools which do not capture the full range of problems or it may be that no amount of treatment will repair the psychological damage that some women experience. Part of the problem in this area is the sensitive nature of the problem, which may require an opaque research approach in order to avoid social desirability response sets. This study investigated these fundamental psychological perspectives using an opaque methodology. If this revealed areas that were not covered by existing QoL studies, then new psychometric measures could be developed, which would have better construct

validity and therefore, would be more accurate measures. If no new psychological issues were revealed, then alternative forms of managing patients' distress would need to be considered. Either way, the study offers insights into progressing treatment in ways that are more clearly and accurately matched to the real nature of the problem. This would have the advantage of making treatment more effective, more targeted and less wasteful.

There are many potential benefits this study may offer to patients, health professionals and organisations. These include improved outcome, satisfaction and social functioning. A reduced spend on pads will free up resources for other needs. A heightened awareness of the issues may encourage people to come forward with UI resulting in reduced suffering and improved QoL through effective management.

CHAPTER 2

JUSTIFICATION FOR THE RESEARCH

This chapter has formed part of several presentations[1-6;6-9], most significantly at the British Society of Urogynaecologists' Annual Research Meeting in London in 2006, which was entitled 'Striving towards tailored urogynaecology management plans'[2]. This was also published in the International Urogynaecology Journal[1].

2.1 Introduction

The following sections outline the justification for this research study. Previous work in this area and related work is reviewed, as are the benefits that the results may afford. The expected outcome is to establish which aspects of incontinence are important to patients, what they expect from surgical treatment, whether or not these expectations are being met by surgical treatment, and which areas are not addressed by current management of incontinence.

This research is the first stage in the development of a tool to apply to patients before treatment to determine which course of treatment they are most likely to benefit from. If psychological features are uncovered then there may be a role for increased psychological input into patients presenting with UI.

2.2 Rationale for the research

UI is a complex problem (see Chapter 3) with many aspects to existing treatments (see Chapter 4), which are effective in many cases. However, anecdotally, there appears to be a number of patients who remain dissatisfied following treatment. Some women seem to undergo series of operations to no avail. Current management is focused on physical symptoms, primarily prevention of urinary leakage. This research is justified to explore the experiences of women suffering UI to gain a deeper understanding of their condition and the treatments currently on offer. Psychosocial factors are important and may be improved following successful conventional treatment. Treatment of psychological problems may in turn help urinary symptoms[10;11]. Treatment of psychological or personality problems is not, however, offered to women as part of their continence management program, certainly in the United Kingdom (UK).

One possible reason for patients' psychological issues following successful UI surgery may relate to unrealistic expectations of treatment. Therefore, one aspect of this thesis will be investigation of expectations. If treatment could be customised to patient need, it may be more successful. To be able to customise it is necessary to capture all the relevant information in order to inform the care plan.

This research is expected to benefit the staff in the urogynaecology unit where the research was conducted, the patients treated locally, the healthcare trust, the primary care trust and the further reaching international urogynaecology community. Potential benefits of this research are in the Table 2.1.

Table 2.1 Potential benefits of this study

Party to benefit	Potential benefit
Patients	Improved outcome Improved satisfaction Less spend on pads Better social functioning Better relationships Improved information
The population	As for patients and also: Heightened awareness and acceptance may lead to earlier help seeking behaviour with reduced suffering Reduced spend on containment products may release funds for other areas
The health trust	Financial saving Improved effectiveness of therapies More efficient health choices Less non-effective treatments and complications

Primary care trust	Financial pad spend Not paying for treatments that are ineffective for individual patients
International urogynaecology community and patients	Sharing information and allowing for benefits in all above categories outside the local study area

The staff in the local urogynaecology department already had their awareness of the psychosocial aspects of their patients increased through involvement with this research project. It may help direct their history taking and make them more efficient at realising the patients' main concerns. The patients may feel heard if staff anticipates psychosocial factors during history taking. It is likely that most patients would appreciate a tailor-made approach. The department of Health (DOH) have highlighted the importance of patient choice and individualised care[12].

2.3 Local continence focus group

A focus group of users of the continence services was performed in the research unit. This aimed to explore women's experiences relating to their condition and management. The results demonstrated that there is a great diversity in how women experience UI and their management and also a variation in people's preferences for their management. The focus group is presented in Chapter 9. Being a taboo subject it is rare for people to talk openly about the condition and the focus group was designed to allow full, honest disclosure. This was aided by excluding clinical staff and the anonymisation of results. Many aspects were explored and this certainly supports further study in this area.

2.4 Outcome oriented research

The DOH National Centre for Health Outcomes Development (NCHOD) is a health service initiative concerned with measuring health and impact of healthcare. Its aim is to make best use of existing information while coordinating development of better information and tools for the future[13]. This indicates that the National Health Service (NHS) feels that more information on outcomes is required and this work will add such information.

There have been various measures used before and after treatment. Some use QoL tools or other standardised measures and goal-oriented research has emerged in recent years. In urogynaecology, Elkadry measured the relationship between achievement of patient goals, overall satisfaction and objective outcome measures in 78 women[14]. Patients were asked to state their goals for surgery before pelvic floor repair or continence operation. Goals were reviewed, clarified and modified by telephone conversations. Three months postoperatively achievement of goals, satisfaction and experience were assessed by telephone. Objective testing was performed at 13 weeks in the form of urodynamics and prolapse quantification. Goals were met by 75% of patients. Patient satisfaction was moderately related to goal achievement while objective cure was not related to satisfaction. Fifty percent of women had at least one unmet goal[14]. The most common issues were postoperative course, urge incontinence, incomplete resolution of symptoms and pain. Eighty percent reported overall satisfaction and number of goals was not related to overall satisfaction. Dissatisfaction was associated with not feeling prepared for surgery.

Urge incontinence or voiding dysfunction affected satisfaction and goal achievement more than objective stress incontinence cure. Objective cure of USI was not related to satisfaction and 83% said they would have the same surgery again[14].

Hullfish used a questionnaire on 33 patients before pelvic floor surgery[15]. They had to list up to five personal goals for surgical outcomes and were subsequently asked to report the degree to which each goal had been met six and twelve months after surgery. Only 42.9% of the goals dealt with urinary or bowel symptoms, the remainder were improving activity (30.2%), general health concerns (12.6%), social relationships and self-image (11.8%) and physical appearance (2.5%). At six weeks 73.9% of goals were met and by 12 weeks most goals were met. Goals relating to social roles, sexuality and self-image took longer to achieve than other goals. It is not known whether or not improvements are maintained longterm[15].

Fitzgerald studied the responsiveness of QoL measurements to change after reconstructive pelvic surgery[16]. The incontinence impact questionnaire (IIQ) and the urogenital distress inventory (UDI) were used for 55 patients who underwent surgery for SUI or pelvic organ prolapse. The study aimed to show whether or not these scales are sensitive to change after continence surgery. Both scales were found to be responsive to objective change in continence status. The UDI may be more useful as an early outcome measure as it assesses the degree of bother caused by urinary symptoms. The IIQ assesses activities of daily living and it may take longer for these to change after surgery[16].

Bidmead investigated the impact of colposuspension on symptoms and QoL in 83 women having colposuspensions for USI[17]. There were improvements in objective measurements (92% in primary surgery and 81% in repeat surgery). QoL scores improved in 95% women using the KHQ while 2.4% recorded deterioration. One patient with persistent irritative symptoms and another with postoperative pain accounted for this, although both were cured of their USI. They also identified some women who had persisting SUI on objective testing but had significant improvements in their QoL[17].

Black assessed the feasibility of collecting data on the impact of surgery on the social lives of women with SUI[18]. Questionnaires were given to 442 women undergoing surgery for USI three, six and 12 months after surgery. Three months after surgery 24% who were in paid employment before surgery were on sick or unpaid leave. The effect on improvement was dependent on preoperative severity. Results were similar three, six and 12 months after surgery. SUI had a less adverse impact on their lives in 75% of subjects, 18% reported no change and 7% felt life was worse. The mean cost of pads fell from £8.59 a month before surgery to £2.99 a month a year after surgery. Protection was not used by 68% women after a year while 11% were spending over £10 a month. Outcome was not affected by whether or not preoperative urodynamics were performed[18].

The above studies highlight interest in the specialty of urogynaecology for attending to psychosocial aspects of evaluating treatments and put an emphasis on QoL rather than ‘dry or not dry’[5]. While this is to be commended it still does not address the

issue of patient selection and how to tailor treatment plans for each patient with her individual expectations, goals and personal constructs. QoL measures and personality tests are reductionist and not wholly appropriate to study the individual's experience of UI and perception of treatment outcomes. What needs to be studied is how the individual construes the problem and the impact of the problem. The focus is somewhere between QoL and personality but to choose to look at these specifically, is already trying to predict what is important to the patient rather than finding it out de novo. The repertory grid technique (see Section 7.3) is one way to assess this. It is particularly useful as it allows factors important to patients to emerge de novo rather than measuring any predetermined theories on a scale.

2.5 Possibilities of alternative treatment approaches

The possible connection between UI and psychosocial factors is completely overlooked in conventional therapies. Only a few studies have looked at psychological treatments. Psychotherapy and hypnotherapy were studied previously, which suggests that the concept of the need to address the psyche in UI has been recognized [10;11;19;19;20]. Educational measures have also been studied in an incontinent population[21]. The studies tend to use these measures on groups of patients with specific urinary conditions rather than selecting women who appear to need their psyche addressed alone or in combination with other treatments. This supports the possible need of a way to detect these women before treatment commences and also, therefore, justifies development of a treatment-planning tool.

2.6 Treatment-seeking personalities

Tyrer examines the way in which personality type determines health management attitudes. Type R is treatment-rejecting and Type S is treatment-seeking and features are summarised in Table 2.2[22]. It is suggested that this typology is useful for those contemplating treatment for patients with personality disorders.

Table 2.2 Treatment-seeking personalities[22]

Type R personality	**Type S personality**
Not presenting with personality as part of their treatment problem	Presenting with a personality problem
Unwillingness to engage in psychological assessment and treatment	Willingness to accept assessment and treatment
Unwillingness to take drug treatments	
Unacceptance of the diagnosis of a personality disorder	Acceptance of a diagnosis of personality disorder
Unmotivated to change	Willingness to change

This study showed that Type R and Type S personality disorders could be diagnosed relatively easily by consensus agreement by a community focused outreach team. The distinction may be useful to make since Type S have a wide range of treatment options available (including psychological and pharmacological). Type R patients on the other hand, would be non-compliant, unmotivated and even resentful of intervention. It may be more appropriate for Type R patients to adjust the environment, rather than trying to adjust the personality[22].This is an example of a novel approach to treatment, based on a personality type rather than a physical

diagnosis alone. It may be possible to identify such factors in women with UI allowing individualized treatment plans to be formulated.

2.7 Conclusions

The above rationale demonstrates a need for supplementary information on qualitative aspects of UI in women and the need for individualized treatments plans. The formulation of methods to help clinicians plan treatment may potentially greatly help with patient selection and satisfaction. Direct attention to psychosocial factors may need to be addressed but this will be explored through the original data collection and analysis in later stages of this thesis.

CHAPTER 3

URINARY INCONTINENCE IN WOMEN

3.1 Introduction

Involuntary leakage of urine is known as urinary incontinence[23] (UI) and affects up to 35% of women. Symptoms are often under-reported[24] and it is, therefore, difficult to accurately measure the prevalence. Under reporting may occur for a variety of reasons including embarrassment, poor awareness of management options, acceptance of the condition with low expectations of treatment and fear of surgery. For some women it may be a mild occasional event, from which they remain unaffected, whilst for others it is an embarrassing, unhygienic and socially isolating problem affecting many aspects of their lives[25-27].

3.2 Definitions

The International Continence Society (ICS) revised the definitions for incontinence in 2002[23] and again in 2009[28]:

- Stress urinary incontinence (SUI) is defined as the complaint of involuntary loss of urine on effort or physical exertion or on sneezing or coughing[28]
- Urgency urinary incontinence (UUI) is involuntary loss of urine associated with urgency[28]
- Overactive bladder (OAB) is urinary urgency, usually accompanied by frequency and nocturia, with or without urgency urinary incontinence, in the absence of urinary tract infection (UTI) or other obvious pathology[28]
- Mixed urinary incontinence (MUI) is the complaint of involuntary loss of urine associated with urgency and also with effort or physical exertion or on sneezing or coughing[23]

3.3 Prevalence

The Department of Health's (DOH) 'Good practice in continence services' document[29] suggests that the problem exists in:

- 5 to 7% of women aged between 15 and 44 years
- 8 to 14% of women aged between 45 and 64 years
- 10 to 20% in women who are 65 years and over

Figures are higher for those in institutions with up to two thirds in nursing homes suffering UI[29]. A study of the natural history of UI in women over the age of 40 years[30] found OAB severity increased with age particularly in those in their sixties. SUI showed two peaks (at 60 and 80 years of age). SUI severity showed a more fluctuating pattern from year to year than OAB.

3.4 The burden of incontinence

UI frequently causes disruption to everyday life for sufferers[31]. It results in considerable inconvenience and embarrassment, affecting relationships, participation in social activities and impairing emotional and psychological well being[25-27;31;32]. There can also be a significant financial burden on individual sufferers in terms of lost livelihoods and purchase of continence products. In 1998 the Continence Foundation estimated the financial burden of incontinence to the NHS in England to be in the region of £353,595,000,[33]. This is comparable to higher profile conditions, such as cardiovascular disease and diabetes[34].

3.5 Risk factors

SUI is due to weakness in the anatomy and structure of pelvic floor muscles, connective tissue and/or innervation. This usually arises as a result of exposure to risk factors (see Table 3.1)[35;36]. Even in the absence of these risk factors anyone can suffer with UI. Young women and those who have never had children are occasionally troubled with UI, probably related to genetics and their tissue type[37].

Table 3.1 Risk factors for Urinary Incontinence

Risk factors for incontinence in women[35;36]
Age
History of nocturnal enuresis or daytime wetting as a child
Pregnancy
Use of forceps in childbirth
Postpartum incontinence beyond three months increases the risk of long term incontinence
Increasing maternal age
Increasing parity
Babies of heavier weights
Chronic coughing

3.6 Making the diagnosis

There are variations between the ways in which individual practitioners manage UI. This may partially be due to mixing of terminology relating to cystometric findings and diagnoses as explained in Table 3.2[28]. The National Institute of Clinical Excellence (NICE) has produced guidelines addressing some of the discrepancies in management[38].

Table 3.2 Clarification of terminology

Symptoms	**Clinical Syndrome**	**Urodynamic diagnosis**
Urinary leakage with increased intra-abdominal pressure (e.g. coughing, exercise)	Stress urinary incontinence (SUI)	Urodynamic stress incontinence (USI)
Urgency with or without urinary frequency, urge incontinence, nocturia	Overactive Bladder (OAB)	Urodynamic detrusor overactivity (UDO)
SUI symptoms and OAB symptoms	Mixed urinary incontinence (MUI)	(MUI) confirmed on urodynamics

History

Women with SUI complain of leakage of urine when their intra-abdominal pressure rises such as with coughing, laughing or sneezing. OAB is characterised by some or all of the following – urgency, frequency, urge incontinence and nocturia[28].

Examination

On vaginal examination, leakage may be seen on coughing with SUI or cough provoked detrusor overactivity (DO). Concurrent prolapse or atrophic vaginitis may be seen on examination. Many women who suffer from UI may have completely normal examinations. Pelvic floor tone can also be assessed by examination and graded according to the Oxford grading system[39].

Simple Investigations

Fluid balance charts are useful in helping to confirm the symptom complex[38]. These allow quantification of frequency, nocturia, leakage, fluid intake and functional capacity. Some women may experience frequency or overflow incontinence because of excessive fluid intake. This situation may be simply remedied by fluid advice. Women who pass small volumes of urine frequently may benefit from bladder retraining to increase their functional capacity.

Urodynamic investigations

Urodynamic investigations are, by definition, required to diagnose USI and UDO and are essential in identifying provoked DO (a form of UUI). In this condition a detrusor contraction occurs following an event such as coughing or standing. Without urodynamics an incorrect diagnosis of SUI may be made based on symptoms alone. It is arguably important to make the correct diagnosis as the treatment for SUI and UUI differs. If surgery is performed for what appears to be SUI when the true aetiology is DO, not only will the surgery potentially not help the condition, it may exacerbate the underlying DO. The patient will also be unnecessarily subject to all the risks that accompany continence surgery.

The use of ambulatory urodynamics remains controversial and involves physical activity after the insertion of bladder and abdominal catheters (in the vagina or rectum). This attempts to mimic normal activities and reproduce symptoms. It may be useful in patients who complain of leakage but urodynamic studies are normal. When comparing ambulatory and conventional urodynamics 63% of patients have additional findings on the ambulatory procedure with DO detected in more cases[38].

Video urodynamics allow the same information to be gathered as urodynamics plus radiological visualisation of the lower urinary tract. This is useful in women who have previously undergone continence surgery or have complex symptoms. Pad tests try to quantify UI but will not identify the aetiology. They are not recommended by NICE[38].

Whilst urinary tract infections (UTIs) are not a major cause of UI, it is prudent to exclude them by a simple urinalysis or a midstream sample for culture, since irritative symptoms secondary to infection may exacerbate the entire picture if there are other urinary complaints[38]. Atypical infections, such as those caused by ureaplasma or mycoplasma, may remain untreated if they are not specifically sought. They may persist despite courses of antibiotics given for proven or suspected UTIs and require a prolonged course of antibiotics for three months.

Fistulae, neurological conditions and renal tract tumours represent rare causes but should not be overlooked. If features such as haematuria or bladder pain occur, appropriate investigation and management should be undertaken[38]. Whilst cystoscopy and biopsy is not a routine investigation for women with UI, it is useful for those with a small functional bladder capacity on urodynamics and irritative symptoms suggestive of interstitial cystitis. It is essential together with imaging (such as ultrasound or magnetic resonance imaging) in those in whom a bladder tumour is suspected or for persisting haematuria.

NICE recommend that UI is categorized into SUI, OAB or mixed UI and

treatment commenced based on history alone. A three day bladder diary is recommended as is a urinalysis. Whilst government policy advocates patient choice[12] the NICE guideline relating to UI[38] does not currently recommend:

- Urodynamics before conservative treatment
- Ultrasound (except to assess residual urine volume)
- Routine use of pad tests or imaging
- Cystoscopy for isolated UI
- Q-tip, Bonney, Marshall and Fluid-Bridge tests

3.7 Conclusion

It is important to make a working diagnosis for patients with UI. Treatment with minimal risk, such as lifestyle advice, pelvic floor exercises and anticholinergic medication should be commenced in the absence of a full urodynamic assessment[38]. It is necessary to seek a diagnosis before embarking on surgery or if treatments are unsuccessful. Over the last five to ten years novel treatments have become available for both UI and the full range of treatment modalities is discussed in Chapter 4.

CHAPTER 4

CURRENT MANAGEMENT OF URINARY INCONTINENCE

4.1 Overview

Women who present complaining of UI require careful evaluation by history taking, clinical examination and investigation as appropriate (see Chapter 3). Management is directed by the information gained from this diagnostic process. The aim of treatment is a resolution of bothersome symptoms leading to an improved quality of life (QoL). Whilst there is widespread acceptance of the impact of UI on QoL, its measurement remains an outcome measure rather than a driver for treatment.

Current treatment options include explanation, support, fluid advice, lifestyle advice, pelvic floor exercises, bladder retraining, medication and surgery[23;38]. A wide range of healthcare providers in primary, secondary and tertiary care including continence advisers, general practitioners, physiotherapists, continence nurse practitioners,

gynaecologists, urologists and urogynaecologists deliver this. Those resistant to treatment will require containment measures such as continence pads. Treatments are often used in combination and it can be difficult to distinguish which treatment has conferred more therapeutic advantage. For example, women with OAB are likely to receive fluid advice, undergo bladder retraining and may also be started on anticholinergic medication concurrently. A woman with MUI may have all these treatments and physiotherapy[38]. Patient selection for each treatment is therefore important. An example of this would be a patient with MUI having successful surgery for the stress component and continuing to be troubled by the OAB symptoms. Urge incontinence can be exacerbated or de novo following pelvic surgery and these pitfalls are well recognised. One option is to tackle the full spectrum of symptoms. The other option is to commence with the predominant symptoms. These decisions can be tailored to each patient in combination with their clinician. Success of treatments can be difficult to measure, as discussed in Section 4.5 and attempts to review effectiveness have been made by NICE[38].

4.2 Conservative treatments

- **Lifestyle measures** include smoking cessation[40], fluid management[41] and correction of morbid obesity[42]. Avoidance of caffeine-containing fluids may also be useful in those with OAB.

- **Constipation** should be avoided and treated[41] as this can affect bladder function and chronic straining can result in pelvic floor weakness with consequent SUI and

vaginal prolapse. In a review it was not possible to find evidence for modifying bowel habit to improve UI, however, observational studies demonstrate associations between bowel disturbance and UI[38].

- **Reviewing concurrent medication** may reveal that patients are taking drugs with an effect on the bladder and changing to a different class of drug or discontinuation, if appropriate, may result in improvement of symptoms. For example:

- Doxazocin, a selective α_1-antagonist prescribed for hypertension, also relaxes the bladder trigone and sphincter muscles
- Neuroleptic medications, such as chlorpromazine and haloperidol, may cause UI by alpha-blocking effects on the urethra
- Diuretics increase urine production and may exacerbate urinary symptoms
- Cholinergic medication can exacerbate DO
- Anticholinergic agents, such as antiparkinsonism drugs, and hyoscyamine used in irritable bowel syndrome can impair emptying and lead to overflow incontinence
- Angiotensin-converting enzyme inhibitors cause a chronic cough in up to 72% of patients taking them, which will increase leakage in women with SUI[43]

- **Pelvic floor muscle training (PFMT)** is effective in up to 65% of cases[12] for SUI and can be optimised when supervised by a specialist physiotherapist[13]. It may also be beneficial for those with OAB or MUI. This can be delivered individually or in a group[44]. Electrical stimulation and vaginal cones can be useful adjuncts[9]. Biofeedback can be used as part of PFMT. The beneficial effects of biofeedback on

psychological burden have been realised and these may be even greater than the effect on UI alone[45].

- **Occlusion devices** such as urethral plugs may allow temporary continence[9]. These may be useful for women who only leak when undertaking physical exercise. Continence rings can be effective for woman with SUI with or without prolapse.

- Bladder retraining is a behavioural treatment where the timing between voids is gradually and systematically increased to improve the functional capacity of the bladder and allow the patient to regain control over the bladder. Results vary between individuals and motivation and supervision may influence compliance with this type of treatment. Supervised bladder retraining confers more benefit than unsupervised training[38]. Inpatient retraining may be useful in a minority of patients who do not respond to outpatient retraining. There is a resource implication when this is being considered.

4.3 Pharmacological treatments

A number of neurotransmitters have been identified as having a modulatory effect on the bladder. These include glutamate, dopamine, enkephalin, serotonin and noradrenaline[46]. Established agents used in treating UUI include anticholinergics such as oxybutynin, tolterodine, and trospium chloride. Newer products include solifenacin, darifenacin and fesoterodine. These drugs are effective in treating UUI but their use is limited because of side effects. The most common side effects include dry mouth, dry eyes and constipation. Their use may be better tolerated with the

introduction of a transdermal preparation of oxybutynin. They are also contraindicated in closed angle glaucoma and caution is advised with ulcerative colitis and myasthenia gravis[47].

Duloxetine is the only drug licensed for the treatment of SUI. It is an inhibitor of serotonin and noradrenaline uptake[48-51]. It is believed to increase efferent output of pudendal motor neurones via stimulation of Onuf's nucleus (α_1-adrenergic and 5 hydroxytryptamine-2 receptors) resulting in enhanced contractility of the rhabdosphincter. This increased urethral sphincter activity reduces leakage due to coughing, laughing and physical activity. Three phase III, double-blind, placebo controlled, randomised trials of 1,625 women showed duloxetine treatment resulted in reduced frequency of incontinence, an increase in voiding intervals and increased QoL[48-51]. Duloxetine represents an alternative for some women who would otherwise have proceeded to incontinence surgery or may not want or be suitable for surgery. The main side effect is nausea (3.1 to 6.4% discontinuation compared to 0% with placebo group)[48-51]. Other side effects include dry mouth, fatigue, insomnia, constipation, headache, dizziness, somnolence and diarrhoea. These were mild to moderate, occurred early and were transient[48-51]. Some negative effects on potassium channels have also been reported.

Imipramine, a tricyclic anti-depressant, blocks the reuptake of adrenaline and serotonin and may increase urethral sphincter closure pressure. This is felt to be related to its effects on α-adrenergic receptors in the urethra. Urinary storage may be increased through centrally decreased detrusor activity. In the bladder imipramine

inhibits noradrenaline reuptake enhancing detrusor muscle relaxation, thereby improving functional bladder capacity[52]. Imipramine has been used as a first-line drug in MUI and as a therapeutic alternative in other types of incontinence, when pharmacological agents have failed[52]. Imipramine therapy may also reduce urinary output. It is a tricyclic antidepressant which inhibits cardiovascular sodium, calcium and potassium channels and can lead to arrhythmias[53], postural hypotension, tachycardia and syncope. Whilst these sequelae are rare, they may need to be born in mind, particularly in the elderly. Phenylpropanolamine and pseudoephidrine are systemic nasal decongestants and are used off label to stimulate the smooth muscle of the urethra and bladder neck and may help patients with SUI. These agents have central nervous system side effects and are contraindicated in uncontrolled hypertension.

The peak prevalence of UI is at the onset of the menopause although this may be a statistical quirk. Local oestrogen hormone replacement therapy (HRT) such as creams or pessaries may ameliorate some of the symptoms of incontinence. Oestrogens are known to have multiple effects in and around the lower urinary tract including enhancing α-adrenergic receptor density and sensitivity, enhancing nerve sensitivity and metabolism and exerting trophic effects on the urethra and the collagen of the pelvic floor and periurethral tissues[54].

4.4 Surgical treatments

The most well established operation for SUI is Burch colposuspension which elevates the bladder neck[38]. The more recently introduced retropubic suspensions such as the

tension-free vaginal tape (TVT) operation is said to exert its effect by supporting the midurethra rather than the bladder neck[38]. These procedures can be complicated by intraoperative blood loss, UTIs, voiding difficulties, de novo DO and new or recurrent prolapse[55]. TVT has comparable short term success rates compared with colposuspension and with the additional advantages of being minimally invasive and having rapid recovery times[55]. Monofilament, macroporous retropubic tapes are recommended by NICE for cases of SUI where conservative management has failed[38]. One study showed an 85% cure rate at five years and preliminary analysis of seven year data showed an 81% cure[56]. Another short term study defining cure as a negative pad test and negative cystometry found cure rates of 66% for TVT and 57% for colposuspension[55]. A 24-month study (n=87) showed an objective cure rate of 91.2%. Subjective primary outcomes determined satisfaction with surgery was high despite the fact that 50% of patients reported some leakage. Satisfaction is therefore not solely dependent on cure of continence. Outcome measures included urodynamic studies, an Incontinence Impact Questionnaire (IIQ-7), the Urogenital Distress Inventory (UDI-6) and a Patient Satisfaction Questionnaire. Prospective evaluation of the IIQ and UDI scores revealed the severity and corresponding burden of patient's UI symptoms were significantly lessened[57]. Since the introduction of TVT at least 15 other 'look-alike' systems have been developed. All rely on the same mechanism of action but vary in method of introduction, properties of tape material and other design details. Second generation trans-obturator tape (TOT) procedures have evolved as an alternative to TVT-like procedures. They are inserted via the obturator fossa, rather than the retropubis[58]. The benefits are a reduced risk of retention and bladder trauma, although the risk of vascular trauma probably remains.

There are as yet no medium or long-term data and the techniques are being subjected to small randomised trials against TVT. NICE supports their use as an alternative to the conventional TVT method provided women are made aware of the lack of long-term outcome data[38]. Other surgical procedures for SUI include sling procedures and injectable bulking agents, which may have a niche role in some women. Most recently the third generation single incision mini slings have been introduced and are undergoing evaluation[59].

Surgery has a much more limited role to play in the management of OAB. Clam cystoplasty involves using a portion of detubularised bowel to increase the size and decrease the contractility of the bladder. The potential complications make this operation an uncommon one in urogynaecology. The bowel is designed for absorption while the bladder is designed for storage. Early complications include mucous plugs, perforation of the neobladder and persistent suprapubic fistula. Late complications include uretero-vesical junction obstruction, vesico-ureteric reflux, vesicle stones, recurrent UTIs and substantial re-operation rates[60;61]. The implanted bowel can become irritated and can develop malignant change at the anastomosis site. Long-term follow up is required. Over the last 10 years clam cystoplasty has almost disappeared due to the advent of the neurotoxin (botulinum toxin A) being injected cystoscopically into the bladder mucosa at multiple sites as a treatment for OAB. This is of proven efficacy in neuropathic DO, but its place in the routine management of refractory DO is currently being evaluated[62-64] (despite widespread uptake). The treatment is reserved for patients with failed other OAB treatments, as it is relatively new with unknown long-term consequences. Results may be short lived

(six to nine months) in the majority, requiring repeat procedures, and can be associated with voiding difficulties. Evidence is limited but suggests an improvement in half of patients[38]. Results of large-scale randomised trials are awaited.

NICE recommends sacral nerve stimulation for women with DO who have not responded to conservative treatments[38]. Urinary diversion is rarely performed and is reserved for cases where no other treatment is successful or suitable[38]. Most recently there has been the introduction of posterior tibial nerve stimulation as a peripheral nerve stimulation[65;66].

4.5 Evaluation of treatment outcome

There are various ways of assessing outcome. While it may seem obvious that the aim of treatment for incontinent patients is a resolution of incontinence, there is debate over what constitutes success. Burgio assessed psychological improvements associated with behavioural and drug treatment of urge incontinence[67]. There were several treatment arms in the study, all of which yielded improvements. Interestingly the authors noted that the reduction of distress was not correlated consistently with a reduction of incontinence[67]. Clinical improvement is not necessarily matched by psychological improvement. For patients' QoL to improve it may be necessary for a behavioural change to occur in addition to achieving continence. Currently there is no medical assistance directed at bringing about a behavioural change.

It is a methodological challenge in research in this field to set outcome measures. This was highlighted in a study reviewing evidence for treatment of OAB in cases

refractory to anti-muscarinics. The authors felt that a standardised measure of treatment success would be useful both in clinical and health economic applications[68].

A randomised controlled trial of four groups - duloxetine alone, PFMT alone, both combined and no treatment, supported the efficacy of combined PFMT and duloxetine in the treatment of women with SUI[69]. The combined therapy group experienced more benefit in frequency of SUI episodes, pad use, QoL and global impression of improvement scores than the group with no active treatment. A systematic review of non-surgical treatments of SUI found PFMT and other physical treatments, estrogens and duloxetine were better than no treatment for SUI[70]. Thirteen reviews of variable quality were included and the case for recommending PFMT and duloxetine was high.

A review concluded that oestrogen therapy subjectively improves SUI and UUI[71]. High dose oestrogen can reduce the total number of voids in 24 hours[71]. This may be the effect of oestrogen on the proprioceptive sensory threshold of the lower urinary tract. Data on combined HRT are limited but suggest that progestogen may negate any benefit[72]. In contrast to this, a multicentre doubled-blind, placebo-controlled, randomised clinical trial of only oral menopausal HRT in over 27,000 postmenopausal women aged between 50 and 79 years of age, participating in the Women's Health Initiative (WHI), was conducted to assess the effects of menopausal HRT on the incidence and severity of symptoms of stress, urge and mixed UI in healthy menopausal women. The study determined that menopausal HRT increased

the incidence of all types of UI at one year among women who were continent at baseline. The risk was highest for SUI, followed by MUI. The authors concluded that menopausal hormone therapy should not be prescribed for the prevention or relief of UI[73]. Since this study deals only with oral HRT preparations it cannot be presumed that this necessarily applies to vaginal preparations.

Current continence surgery in those with SUI is felt to have a success rate of around 80% although lower success rates have also been suggested, possibly reflecting the debate over what constitutes a cure[55]. Physiotherapy is thought to be sufficient treatment for around 50% of women with SUI but research outcomes vary considerably and up to 85% has been quoted as a subjective and objective cure rate[38].

Pharmacological therapeutic benefits need to be weighed against side effects for a true measure of benefit[74-77]. For example, some women may have intolerable anticholinergic side effects from medication far outweighing greatly improved OAB symptoms. Outcome measures in studies must reflect this phenomenon.

It may be that some women may not change their behaviour and habits even when their treatment appears to be successful or has conferred a subjective improvement. For example, it is possible that some women who no longer leak urine may still wear a pad ‘just in case’ or are still afraid to stray away from where they know there is a toilet. Their lives may not be significantly improved even though they have been ‘cured’. This theory will be explored further in this study.

Objective measurement of cure, using cystometric urodynamics or pad testing, allows a standardised approach but does not, necessarily reflect patients' satisfaction with their procedure or mimic their daily lives. There is a variation in success rates of operations when patients and surgeons are asked their opinions, with the surgeons' success rates usually exceeding that of the patients. Two hundred and ninety nine questionnaires (52.7% response rate) distributed to clinicians were compared to a previously published questionnaire completed by patients[78]. The questionnaire asked about expectations following treatment and use of outcome measures. Overall, 85.9% of responding clinicians felt a good improvement in urinary symptoms, so that they no longer interfered with the patient's QoL, was a realistic outcome. The majority of clinicians thought small or infrequent episodes of leakage were acceptable following treatment, although frequent or large leaks were not. Irritative urinary symptoms such as urgency and urge incontinence were felt to be less acceptable as were frequency and nocturia. Overall, there was found to be poor agreement between clinicians and patients' attitudes to acceptability of symptoms and this agreement was no better than chance. In the research setting, 61% felt both subjective and objective outcome measures should be used, whereas in clinical practice, 42% thought subjective improvement alone, and 36% subjective improvement in QoL, were appropriate. It was felt that clinicians have realistic expectations following treatment, although there is poor agreement with those expectations expressed by patients. The authors conclude that these findings may help to explain why patients may be disappointed regarding treatment outcomes and why there may be a difference between subjective clinical impression of success and

patient satisfaction. The unilateral approach to assessing success, such as asking the surgeon alone, is not likely to give a true measure of patient satisfaction. The patient perspective is discussed in Section 4.6.

A further study to compare patients' and physicians' views on improvements resulting from behavioural management for incontinence found that physicians underestimate clinically meaningful changes with a concordance of only 57% between physicians and patients[79]. This study was on global impression of improvement with patients reporting improvement more often than clinicians.

4.6 The patient perspective

Subjective success is perhaps a more appropriate measure since this is what patients are interested in and may be used in preoperative counselling. A study of 442 women looked at several aspects of women's lives that may be affected by surgery for SUI[18]. Women were given questionnaires before surgery and then three, six and 12 months after surgery. Three months after surgery 24% who were in paid employment before surgery were on sick or unpaid leave. The effect on improvement was dependent on preoperative severity. Results were similar three, six and 12 months after surgery. Seventy-five per cent reported that SUI had less adverse impact on their lives, 18% reported no change and 7% felt life was worse. The mean cost of pads and towels fell from £8.59 a month before surgery to £2.99 a month, a year after surgery. After a year 68% women were not using protection while 11% were spending over £10 a month.

QoL tools were developed to assess the impact of disease on a population and are initially extremely helpful as population based research tools. They have been devised for ease of administration and to standardise information collection. The use of standardised QoL questionnaires allows equivalent information to be collected from different people. They allow a wide variety of factors to be examined which is an advantage. They are, however, perhaps too simplistic, since they assume their measures can be applied to everyone universally. They are also reductionist, because they distil a whole wealth of experience into a limited number of simple measurable constructs. Most are self-completing written questionnaires but variations include computerised completion. Some are general health questionnaires while others are disease specific and have an emphasis on pelvic floor symptoms.

Notwithstanding these limitations, the King's Health questionnaire (KHQ) is a continence specific QoL tool that is being increasingly adopted to evaluate outcomes. The areas (known as domains) covered in the KHQ are general health perceptions, incontinence impact, role limitations, physical limitations, social limitations, personal relationships, emotions, sleep/energy and severity measures. Subsequent refinements to the KHQ, with new analysis, has allowed this to become more important at an individual level[80]. QoL questionnaires, however, remain as tools for measuring impact of disease and response to treatment and therefore are measures of outcome and offer no information on suitability of patients for particular treatment types. They also do not capture experience of the disease or treatment. They tend to be very limited, reducing the depth and breadth of information that is relevant and which is salient to the patient and clinician. Moreover, since there is little agreement

as to what constitutes a successful treatment outcome, their content and relevance may be debatable. Certainly, the individual variability in women's assessment of their condition and its impact makes a strong case for using idiographic measures rather than normal referenced tools. Confirmation of their questionable value comes from a study by Ternent used a questionnaire to generate an index of areas of importance to 188 women with SUI. This did not correlate well with most of the domains on the KHQ and the authors conclude that QoL instruments may not be capturing areas of concern to women with SUI[81].

The KHQ was compared to an objective demonstration of cure by video cystourethrography on 83 women undergoing colposuspension for USI[17]. There was an improvement in objective measurements (by video cystourethrography) of 92% in primary surgery and 81% in repeat surgery. QoL scores improved in 95% women using the KHQ while 2.4% recorded deterioration in QoL scores. This 2.4% comprised two patients, one of whom suffered persistent irritative urinary symptoms and one who had postoperative pain although both were cured of their USI. They also identified some women who, despite having persisting SUI on objective testing, had a significant improvement in their QoL scores.

The DOH NCHOD working group has recommended the collection of symptom and QoL data before and six months after treatment. KHQ appears to be an appropriate tool for such assessment. Alternative tools are available to assess QoL. There are variations in how sensitive to change they are and how long after treatment a change may be observed[16].

The IIQ and UDI were used to assess 55 patients undergoing surgery for SUI or pelvic organ prolapse. Both scales were found to be responsive to objective change in continence status. UDI may be more useful as an early outcome measure as it assesses the degree of bother caused by urinary symptoms. IIQ assesses activities of daily living and it may take longer for these to change after surgery.

An alternative approach to making objective measurements, objective or subjective enquiry or a QoL questionnaire is to use individual patient goals to assess outcome[14]. Such an approach would enable patient improvements to be assessed against individual objectives and criteria, and would facilitate some customization of patient management. In 78 women the relationship between achievement of patient goals, overall satisfaction and objective outcome were measured[14]. Patients were asked to state their goals for surgery before their pelvic floor repair or continence operation. Goals were reviewed, clarified and modified by telephone conversation. Three months postoperatively achievement of goals, satisfaction and experience were assessed by telephone. Objective testing was performed at 13 weeks in the form of urodynamics and prolapse quantification. It was found that 75% met most of their goals. Patient satisfaction was moderately related to goal achievement while objective cure was not related to satisfaction. Fifty percent of women had at least one unmet goal. The most common unmet goals were postoperative course, ongoing urge incontinence, incomplete resolution of symptoms and pain while 80% reported overall satisfaction. The number of goals stated was not related to overall satisfaction. It was found that dissatisfaction was associated with not feeling prepared

for surgery. Urge incontinence or voiding dysfunction affected satisfaction and goal achievement more than objective stress incontinence cure. Objective cure of USI was not related to satisfaction and 83% said they would have the same surgery again.

In another goal oriented study, a pre-operative questionnaire was given to 33 patients who were going to have pelvic floor surgery[15]. The questionnaire asks participants to list up to five personal goals for surgical outcomes. Six and 12 weeks after surgery they were asked to report the degree to which each goal had been met. Goals involved the following:

- 42.9% concerned urinary or bowel symptoms
- 30.3% concerned improving activity
- 12.6% concerned general health concerns
- 11.8% concerned social relationships and self-image
- 2.5% concerned physical appearance

At six weeks 73.9% of goals were met and by 12 weeks most goals had been met. Goals relating to social roles, sexuality and self-image took longer to achieve than other goals. Longer-term follow-up has not been studied in this paper and it is not known whether or not improvements are maintained.

What these studies have failed to do, however, is try and assess whether the chosen treatments are likely to meet the patient goals on an individual level, or whether the treatment was varied depending on the goals. This is an approach, which does not appear to have been studied. It is the individualized aspect of treatment choices and experience of treatment, which is studied later in this thesis. These studies also fail to

assess how goals may change over time, while the measures fail to capture the full range of patient experiences.

4.7 Treatment planning

Treatment plans must be formulated carefully, taking into account many factors including the diagnosis, the opinion of the patient, the opinion of the clinician and resources. NICE guidance advises on UI management issues[38]. There are several choices of treatment for each condition in urogynaecology and indeed there is substantial overlap of conditions. Incontinence treatment is seldom if ever an absolute emergency and conditions often develop over months, years and in some cases decades. There is rarely a need to rush headlong into a treatment plan, particularly surgery, with its inherent risks and potential complications. On the other hand, many women may have put up with their symptoms for years and by the time they seek help are desperate for a solution to their problems. Further investigations and clarification of symptoms may sometimes seem an unwelcome delay to some women seeking a quick fix solution whilst others may appreciate a thorough assessment and stepwise management plan. Patients' attitudes to their management will be examined later in this study.

Patients' preferences for treatment may be based on many factors including their own understanding of their condition, perceived benefits and risks of treatment offered, their past personal experiences, experiences of friends or family and media reports. It can be challenging in a consultation with time limits to tease out all of these factors and establish exactly on what each patient bases her preferences. While

some of her influences may be well founded others may be based on poor evidence or anecdote. The specific preferences and attitudes to treatment will be one of the core focuses of this thesis.

Cognitive psychology has studied how people understand risk and how information is used in decision-making. People tend to use short cuts, known as heuristics, to simplify the decision making process. These short cuts, however, can lead to biases[82]. Many patients have poor comprehension and recall of risk information. Risk, in general, is considered to be the product of the probability of an outcome and the severity of that outcome[82]. The understanding of both aspects of risk is crucial to patients' decision-making processes. In addition to understanding how likely an adverse event is to happen, each patient needs to understand the nature of the risk and what it would mean to their life if it were to happen to them. An example of risk perception is that sometimes the risk of rare causes of death, such as murder, is overestimated, while common causes, such as stroke, are underestimated. Other factors also influence the perception of risk, including the extent to which people can control that risk, whether the risk is perceived to be immediate or in the future and how catastrophic the risk is felt to be[82]. The way in which the risk is presented, or framed, is also important and never more so than in medicine. People are influenced, for example, by whether risks are expressed as survival rates or mortality rates. The source of the information is also important with more weight given to information from a source considered trustworthy by the patient[82].

Patient choice is also important when it comes to planning management. The DOH published a report in 2007-2008, 'Choice Matters; putting patients in control'. Much of this surrounds how patients may choose who provides their healthcare. The importance of information to enable these choices to be made is also highlighted[12]. This document also states that choice is for everyone and mentions that a 'one size fits all' approach has previously been used in healthcare but acknowledges that people's health and well-being may be improved while improving efficiency in the health service. A direct quote from the document follows:

We want to open up the debate on how to change cultures so that shared decision making between patients and clinicians becomes normal good practice.

Langford assessed 100 women's expectations of SUI treatment. The results were:

- 22% expected a complete cure
- 57% expected a good improvement
- 12% expect to be able to cope better
- 22% found major surgery acceptable
- 39% found minor surgery acceptable
- 32% found a clinical procedure acceptable
- 7% found medication acceptable
- 71% found a minor surgery (e.g. transobturator tape or collagen injection) most desirable

The authors felt choices regarding treatment were influenced by age, severity and QoL and suggest it may be beneficial to include these factors in treatment planning[83].

It may be possible to study patients' preferences for treatment to try to understand why these differences in preferences exist. The focus on the individual and her experience of her problem make the use of universal, population-based instruments less relevant than idiographic techniques of assessment. The repertory grid technique, with its focus on the individual's construction of personal experience, has been suggested as a suitable tool for this and this method is central to this study[84].

Other methods for examining patient preferences use items chosen by the experimenter and then rated by the patient. Unfortunately these items may have little meaning to the patient in psychological terms. In the repertory grid technique the patient selects the items herself, enhancing their relevance and appropriateness to the patient.

Decisions about treatment will be made by agreement between patient and clinician. The factors affecting patients' preferences have been discussed but clinicians' preferences also are subject to variation. This has been illustrated by studies comparing patient and clinician preferences and discrepancy has been found. Many of these studies, however, use hypothetical situations to ask about decisions, rather than real time decisions when the patient is suffering symptoms. This may yield different results[85].

UI can be seen as a chronic condition. Patient career and trajectory provide a framework allowing the description of the impact and phases of chronic illness[86]. It also identifies the consequent work required by sufferers and additionally their carers.

Work by Roe[86] aimed to determine the impact of incontinence on individual patients and to identify the impact of effective and ineffective health interventions for the management of incontinence on illness trajectory and healthcare.

Chronic illnesses have recognised phases. First an initial recovery from acute episodes, then periods of stability or remission and then a deteriorating phase[86]. Part of a chronic illness is coming to terms, normalising and adjusting in order to accept the illness. The progression to adjustment, adaptation and acceptance is related to coping, strategy and style. Coping is a cognitive process where the individual learns to tolerate the condition. Strategy involves managing the condition to gain control. Style refers to how people present and respond to features of their condition or treatment. Routes of referral and healthcare may also be important in improving presentation and help seeking. It is also suggested that multiple referrals to multiple disciplines is more effective in allowing patients to access appropriate care than single referrals. This may need to be balanced against a potential lack of a cohesive management plan, duplication and increased resources.

Care plans may also be appropriate for those with UI. The DOH in 1995 advised that people with continuing community care needs should have written explicit care plans. The development of individual care plans for people with UI may assist in overall management and facilitate coordination and evaluation of care. Management techniques may help people to deal with their situation. These may be simple or very complex. Some patients may get a sense of control and confidence by being allowed to choose the treatment they prefer.

Another aspect of the treatment plan is identifying cases. This involves conveying information to patients in order to encourage them to present with the condition or initiate self-help initiatives. A small study randomised people to two different methods of information giving. One was individual instruction backed up with written information and the other was written information only. There was no difference between the groups in their self-referral rates. In both groups the main reason for not referring themselves to a professional was a preference for self help. Impressively, 88% of those initiating self help behaviours reported a subjective improvement in their frequency or volume of incontinence[23;87].

4.8 Conclusion

Treatment decisions are traditionally based on symptoms and/or cystometric urodynamics. Most assessment tools measure outcome and little or no work has been done on decision-making and treatment choice. Other factors may be useful in the future to inform treatment decisions. Over the last five to ten years new treatments have become available for SUI, UUI and MUI. It will be exciting to watch new treatments being incorporated into everyday clinical practice.

The ongoing debate about how best to evaluate treatment is likely to continue and there is a need for a consensus over which tools to use so that valid and valuable comparisons can be made. Broadly speaking there are two approaches. The first approach is to evaluate which is the best treatment based on quantitative research and apply this treatment to all. The second is to try to assess merits of each

treatment and choose the right treatment for the patient by balancing the risk of side effects and complications against objective success rates. Individual patients' experiences must be important in how they feel about their treatments. This may be a neglected area of study that could potentially revolutionise treatment planning. More important than evaluating treatment performed is the actual choice of treatment for each patient, and it is in this area that this project will assist. Expectations may need to be addressed directly to prevent a mismatch with consequent dissatisfaction and treatment failure.

CHAPTER 5

DESIGN CONTEXT

5.1 Disciplinary background

The project is set in the context of the clinical speciality of gynaecology. Urogynaecology is a subspecialty of gynaecology and therefore all subjects are female. Males also experience UI but they are excluded from gynaecology and would traditionally attend professionals allied to urology, which is a subspecialty of surgery.

The primary researcher and author had over six years' clinical experience in obstetrics and gynaecology and had experienced patient contact throughout that time. A general interest in urogynaecology was present throughout this time but not exclusively until the time of the research project. This experience was in many different hospitals in several different regions, all within the UK.

The two advisors and supervisors on the project came from diverse backgrounds and this was paramount in gaining different perspectives for the design, aims, interpretation and potential applications of the project. Theories were developed through joint collaboration, allowing development of methods and perspectives.

One supervisor was from a general gynaecological background with a tertiary consultant level special interest in urogynaecology. He has an active role in clinical research including a period in fulltime research and ongoing industry driven clinical research. He has supervised several other researchers during their higher degrees in topics related to urogynacology. He is a full-time clinician meeting patients, such as the subjects in this study, on a daily basis. He does not have any formal background in psychology but did work in a unit where QoL was being studied. He was the main driver behind setting up this project based on his anecdotal experiences.

The other supervisor had a background in psychology and is a University Professor in Health Sciences. She has a wealth of academic expertise and has supervised many researchers in the field of health sciences. She has experience in different methodologies and advises on the suitability of these in this project. She has seen psychological aspects of healthcare studied in other medical disciplines, but does not have experience in the field of UI. She has seen how studies in other disciplines have been able to inform healthcare issues, for example the use of CBT for frequent primary care attenders and their attendance falling thereafter. She is an employee of the University of Birmingham where this study is registered.

5.2 Research setting

The entire study was conducted in Birmingham Women's Hospital (BWH), a tertiary referral centre, with 176 beds, and a university teaching hospital for obstetrics and gynaecology. It employs around 1,400 members of staff and aims '*To be the first*

choice for women and babies, and to be a place where people want to work.' BWH provides a range of inpatient and outpatient services for women and babies. There are strong medical and nursing links with the University of Birmingham and Birmingham City University. The main services are gynaecology, maternity, fertility, neonatal intensive care and genetics. There are 5,185 gynaecology patients seen at BWH per year. With 10% of the UK population living in the West Midlands, it is estimated that 500,000 women in the area suffer with UI. BWH provides secondary and tertiary care in urogynaecology offering a wide variety of facilities. The urogynaecology service at BWH was established in 1998. The service has dedicated physiotherapy and strong links with urology and colorectal colleagues. The staffing of the unit, at the time of data collection for this study, comprised a consultant lead, an additional consultant, two urogynaecology nursing sisters, a perineal trauma specialist midwife, two research fellows and physiotherapy support. Junior medical staff rotate through the department. A subspecialty trainee in urogynaecology was appointed shortly after completion of data collection.

There are two consultant continence clinics per week and the two nursing sisters in the urogynaecology department run their own continence clinics three times per week. Nurse led continence clinics are extensively used to guide women in lifestyle changes, bladder retraining and to provide support. They also teach intermittent self catheterisation (ISC) to women as required. There are several urodynamic sessions per week where full assessments are made, treatment plans formulated and initiated at the time of urodynamics, where possible, resulting in a 'one stop shop'. Video-urodynamics is reserved for the investigation of women whose symptoms have not

been adequately assessed by standard urodynamics, who have not responded to conventional treatments, or who have had failed continence surgery. The urogynaecology unit is able to perform ambulatory urodynamics for women whose symptoms are severe but their urodynamics have not shown a definitive diagnosis.

The physiotherapy department provides well-equipped specialised treatment for a wide variety of conditions, including SUI and MUI and support of women undergoing bladder retraining. BWH runs a programme of inpatient bladder retraining. There are two dedicated beds on the general gynaecology inpatient ward for detailed assessment of women refractory to outpatient management and bladder retraining. They are given a tailor-made voiding regimen and medication if required. An audit of this service showed that of 114 women, 23% were subjectively cured of their symptoms, 36% reported improvement, 27% reported no improvement, and 14% were worse[88].

A full armamentarium of surgical procedures is available. Investigative surgery, such as cystoscopy with biopsy and examination under anaesthetic, is usually carried out on a day case basis whilst those having definitive surgery usually stay longer. Colposuspension and TVT are offered as treatments for USI. Pelvic floor repairs and hysterectomy are offered for uterovaginal prolapse and sacrospinous fixation for vault prolapse. Newer procedures including transobturator tape (TOT), botulinum toxin injection, and mesh for repeat prolapse surgery are also offered for selected cases, sometimes in the context of a randomised controlled trial (RCT).

A patient support group, facilitated by the nursing sisters, has been very helpful for some women. This in turn helps the department by providing valuable feedback on ideas on service development. There are weekly multidisciplinary meetings where cases are discussed between medical, nursing and physiotherapy staff to formulate management plans. This is a valuable opportunity for patients to benefit from consensus opinions and is also educational for participating staff. All of the subjects in this study were attending the department of urogynaecology for treatment. What is new is the depth to which their experiences are being explored. All NHS appointments are time allocated whereas all encounters with subjects were not time limited by the researcher.

5.3 Methodology context

The project was conducted prospectively. Many of the interactions, however, involved retrospective reflection. Mostly qualitative methods were used but some quantitative elements were included. Randomised controlled trials (RCT) are currently the gold standard in experimental research[89]. The RCT is a way of evaluating the effectiveness of interventions. It establishes cause and effect relationships and has several characteristics[89].

- RCTs are controlled
- The participants are randomly allocated to either an active intervention or to no treatment
- Several treatment groups may be compared
- There are pre-specified inclusion and exclusion criteria

- The groups are considered to be comparable because subjects are randomly assigned to the experimental and control groups
- There should be no bias in any of the selection procedures as they are carried out according to certain defined conventions
- Ideally neither the researcher nor the participant know which group they have been allocated to (double blind). Sometimes this is not possible and only the subject is unaware (blinded)
- Procedures are standardised

Because of these features, RCT methodology is restricted to particular topics and as such its value is restricted to experiments that can be set up to incorporate these criteria. Particular treatments lend themselves to RCTs. Medication is relatively easy to evaluate by RCTs. Medication research may also attract funding more easily as pharmaceutical companies require evidence. Most national guidelines or hospital protocols are based on evidence based medicine and since robust trials such as RCTs are more likely to be performed on particular treatments this may bias the inclusion of certain treatments. Treatments that are more difficult to measure may not be studied as much or at all and may be excluded from guidelines[89]. RCTs may also be performed for political and economic reasons and there are numerous examples of fraudulent results in order to meet the researcher's or sponsor's needs[89].

Reductionist approaches, such as the RCT, are of little value in measuring complex multifactorial treatments. For example when a patient is nursed there are many aspects of patient care that are attended to. The personalities and relationship of the

nurse and patient may influence the outcome of the nursing. To measure this by an RCT would be virtually impossible as there are so many variables. In summary the quest to provide good evidence based research to write guidelines and enable patients to be more fully informed about treatment options may actually result in a narrowed range of available treatment options. Additional methods are therefore necessary to be able to explore treatments and aspects of care not amenable to RCTs.

The RCT is a type of quantitative research allowing the collection of numerical data and statistical analysis to express treatment effectiveness. While this is high-level evidence it is incapable of capturing information of an individual nature. It emphasises the use of large samples and is perceived as a gathering of facts[90]. Qualitative research is capable of obtaining highly personal, individualised experiential information and opinion. Quantitative methods may be inadequate for this purpose, although they are appropriate for measuring the prevalence of certain preset factors, such as symptoms. Qualitative methods may be the approach of choice to explore incontinence in depth and discover subjective information, which is unknown and cannot, therefore, be preset. The focus tends to be on exploring, in as much detail as possible, smaller numbers of instances or examples seen as being interesting or enlightening. The aim is to achieve depth rather than breadth. Qualitative data may offer more detail about the subject under consideration, while quantitative data appear to provide a more objective, broad-brush picture. The accuracy of qualitative data may be reduced further in research as the data are summarised and the main points drawn out[90].

The distinction between words and numbers may not be as precise or rigid as it initially sounds and the distinction between qualitative and quantitative data can become blurred. Sometimes numbers are assigned to subjective responses and while interview-based research may appear to be wholly qualitative, quantitative methods can be used to analyse the interviews. Neither type of data is better or more accurate but each has to be assessed on its own merits for the area under study. The differences between qualitative and quantitative data is illustrated in Table 5.1[90].

Table 5.1 Comparison of qualitative and quantitative research

Qualitative research[90]	**Quantitative research**
Concerned with understanding behaviours from subjects' own frames of reference	Seek the facts or causes of social phenomena
Naturalistic and uncontrolled observation	Obtrusive and controlled measurement
Subjective	Objective
Close to the data – the insider's perspective	Removed from the data – the outsider's perspective
Grounded, discovery-oriented, exploratory, expansionist, descriptive, inductive	Ungrounded, verification oriented, reductionist, hypothetico-deductive
Process oriented	Outcome oriented
Valid, real, rich, deep data	Reliable, hard, replicable data
Ungeneralizable	Generalizable
Single case studies acceptable	Multiple case studies

Holistic	Particularistic
Assume a dynamic reality	Assume a stable reality

The repertory grid (see Chapter 7) and interviewing techniques were used as the primary methodology. Visual analogue scales (VAS) and a continence specific QoL questionnaire (the Kings Health Questionnaire) provided additional information in one cohort of subjects (study group 3). The KHQ is a validated disease specific questionnaire felt to be an appropriate tool to look at QoL in this study for only the group studied both before and after treatment (study group 3) in order to relate different outcome measures of success[80]. The KHQ is now in common use in the UK and is available in many languages for international and multicultural use.

A VAS is a measurement instrument that measures something on a scale, thereby providing continuous data. A spectrum is more representative for some symptoms, such as pain, rather than a broad classification into mild, moderate and severe. The VAS is usually an unmarked 100mm horizontal line labelled at each end with word descriptors. The VAS score is determined by measuring the distance from the left hand side of the line to where the subject marks[91]. The VAS is particularly useful in measuring change within individuals. Caution should be exercised when looking at precise scores as too much can be read into them and it has been suggested that rank ordering may be more informative. There are debates as to whether the VAS is ratio or ordinal data[92]. In this study the VAS was used as an adjunct to interviews and repertory grids rather than as a fundamental research tool. Objective testing of cure

was included for one group of subjects (group 3) and this comprised cystometric urodynamics. This group had interviews before and after surgery for SUI.

Themes derived from the literature review on experiences of incontinence were also incorporated into the data along with evidence derived from a focus group held within the BWH. The methodology is outlined more fully in Chapter 6. Additional useful information was also extracted from these sources for the purpose of improving management and this is discussed in Chapter 16.

5.4 Context of other research in the field

Some work has been published on peoples' experience of UI and this will be explored in Chapter 8. A focus group conducted in the research unit explores local women's experiences of their condition and treatment received. Other researchers have acknowledged that different patients have different goals for treatments[93] of UI and there has also been work on QoL, which acknowledges that there is more to a successful outcome than whether a patients has less urinary leakage[80].

CHAPTER 6

DESIGN METHODS

Part of this chapter was presented orally to the International Continence Society (ICS) in Christchurch, New Zealand in 2006[3] entitled 'Development of a treatment planning tool in urogynaecology. Use of the repertory grid technique'.

6.1 Introduction

The methods in this thesis were devised to fulfil the aims and objectives of the study. This included both the short term and long term objectives. It was acknowledged that there was no known similar work in this field and therefore that the methodology may need to evolve during the course of the study. A brief summary of the research plan is outlined in Chapter 1 and tabulated in Section 6.2. The full research proposal, as

submitted for peer review, to the hospital research and development department, to the university and to the ethics committees is in Appendix I. The subsequent sections (6.3 to 6.10) discuss how and why the methodology evolved and explores each type of tool used in more detail. Section 6.11 is a critique of the methods used. The author has presented and published some of the methodology used internationally together with preliminary results[1-3;5].

6.2 Research outline

- **Project aims**

This project aimed to identify a range of psychological factors in women who experience dissatisfaction. The aim was not necessarily to find common factors, rather to identify individual factors using repertory grids. Psychological factors may inform treatment but if they are not covered by existing QoL measures, then alternative psychometric measures would need to be developed as well. If the measuring tools are not measuring what they should be measuring then they will provide misleading information, leading to wasteful and ineffective treatment and management.

There was a study made of women with UI in general and in addition a focus on those with stress urinary incontinence (SUI) to find out what aspects were left untreated or unresolved by current treatments. This was the preliminary stage of what is expected to be a much larger project in this field to develop a treatment-planning tool.

- **Objectives**

1.To find out what is known about the association between urinary problems and psychological problems

2.To find out what is known about the effectiveness of psychological interventions to augment treatment for patients suffering urinary incontinence

3.To find out what patients' experiences are of urinary incontinence and its treatment

4.To find out what aspects of urinary incontinence are not altered by current treatment

5.To find out what patients' expectations of incontinence surgery are

6.To find out why some patients who are 'cured' of incontinence still do not seem to be satisfied with their outcome

7. The findings will inform future projects. Identified themes could inform a future screening tool to apply to incontinent patients to aid treatment planning

- **Methods**

Table 6.1 Methods for study stages

Stage	Description	Purpose	Method	Chapter
1	Literature search 1	To establish what was published surrounding women's experiences of UI and extract themes for development of a	Electronic searches	8

		treatment planning tool		
2	Literature search 2	To explore associations between urinary problems and psychological problems	Electronic searches	8
3	Literature search 3	To identify psychotherapeutic measures used in the management of patients with UI	Electronic searches	8
4	Focus group	To identify themes relating to women's experiences of UI and its management and extract themes for development of a treatment planning tool	Summary of themes from focus group report	9
5	Pilot patient assessments	To refine the techniques of performing repertory grids and qualitative interviews and gather themes for the development of a treatment planning tool	Repertory grids and qualitative interviews. Thematic analysis.	10

6	Group 1 patients (General)	To explore women's experiences of UI and its management and extract themes for the treatment planning tool	Repertory grids and qualitative interviews. Thematic analysis.	11
7	Group 2 patients (Postoperative)	To explore women's experiences of UI and its management with a greater emphasis on surgical treatment of USI	Repertory grids and qualitative interviews. Thematic analysis.	12
8	Group 3 patients (Preoperative and postoperative)	To examine, as case studies, each women prior to surgery for USI and compare her with herself after surgery for the purpose of identifying why women who are cured of UI remain dissatisfied	Preoperatively: repertory grids, KHQ, situations affecting incontinence and pad use questionnaire, urodynamics. Postoperatively: as per preoperatively and a VAS about subjective cure and satisfaction.	13
9	Development of themes	To provide content validity for development	Combining thematic analyses from	15

		of a treatment planning tool	experiential literature, focus group, interviews and repertory grids.	
10	Identification of other potential improvements	To improve patient satisfaction and inform future practice and future research	Scrutinising interviews, literature and the focus group for suggestions from patients and points of dissatisfaction	15

- **Stages 1, 2 and 3 – Literature reviews 1, 2 and 3**

These were performed on Medline and Psychinfo electronic databases using search terms including 'incontinence' and 'psychological tests'. The review was intermittently updated using the Pubmed electronic resource. Reviews on women's experiences of UI, links between psychological and urinary problems and psychotherapeutic interventions in UI were performed. Thematic analysis of the experiential literature was performed. The literature reviews are discussed further in Chapter 8.

- **Stage 4 – Focus group**

The hospital focus group was conducted prior to the start of this study. The report was examined for themes of women's experiences of UI and their treatment. This was to strengthen the content of the final treatment-planning tool and is discussed further in Chapter 9.

- **Stage 5 – Pilot patient assessments**

Six preliminary pilot interviews were performed on women with urogynaecology problems using the repertory grid technique. These were followed by detailed interviews regarding patients' experiences of incontinence and their expectations and experiences of treatment. This action research allowed development of the technique of performing repertory grids and checking of the feasibility of the study and its methods. As each interview took place the process was reviewed and modified to optimise data collection. The repertory grids allowed the subjects to describe events and experiences in their own terms in line with personal construct theories. This is a very individual and in-depth interview process and is not amenable to large-scale experimental design. A small number of interviews generate a lot of qualitative and quantitative data. These interviews were included in the first group of 20 general patients with UI so that their valuable contribution to this area was not lost. The pilot group action research is presented in Chapter 10.

- **Stage 6 – Group 1 patients**

To find out what patients' experiences are of UI and its treatment, semi-structured interviews with three groups of patients were performed. The participants were all adult women recruited from the urogynaecology services at BWH. Repertory grids do not require large random samples and participant selection may be non-random, purposive and opportunistic as in this study. Some subjects were identified at urogynaecology clinics or during inpatient bladder retraining. There were 20 women in this group (including the six women interviewed in the pilot phase). They had

general UI problems and were a heterogeneous group, comprising women with OAB, SUI and MUI who may have had various different treatments. The only commonality within this group was that they were female and were attending the BWH continence services. The interviews and repertory grids were examined to find out about women's experiences UI and their treatment to date.

- **Stage 7 – Group 2 patients**

These women were interviewed for the purpose of focusing on surgical management of USI. They were recruited from BWH continence services as having had SUI continence surgery at any time previously. They may have had multiple treatments and their SUI surgery may have been recent or many years ago. The focus of the interview was their experience rather than scientific detail of their actual surgery. There were 20 women in this group and each underwent repertory grids and a qualitative interview as detailed in Chapter 11.

- **Stage 8 – Group 3 patients**

The third group of patients are studied individually (as case studies) and factors extracted relating to why some patients who are cured of incontinence still do not seem to be satisfied with their outcome. This patient group had both objective and subjective measures of cure. Preoperatively 22 patients were recruited to this group but only 14 of them had surgery and attended for postoperative evaluation. The results were based on these 14 women. This group of women underwent repertory grids and qualitative interviews in a similar fashion to groups 1 and 2 but they also

underwent additional measures (see Table 6.1) to try to assess cure and identify changes occurring after treatment. This group is presented in Chapter 13.

- **Stage 9 – Development of themes**

Themes with which to develop a screening tool to apply to incontinent patients to determine whether they need additional psychological support or educational measures and to predict whether or not they are likely to benefit from different incontinence treatments were generated from the experiential literature, focus group and interviews. Each repertory grid was analysed individually to ascertain the pattern of associations. The constructs from the repertory grids were thematically analysed by recognised methods[94]. Themes from the literature are presented in Chapter 8. Themes from the focus group are presented in Chapter 9. Themes from repertory grids and qualitative interviews from Groups 1, 2 and 3 are presented in Chapters 11, 12 and 13 respectively. In Chapter 15 a combined thematic analysis is presented.

- **Stage 10 – Identification of other potential improvements**

Through the course of reviewing the literature, focus group and interviews there were a great many observations made. These are discussed in Chapter 15.

- **Expected outcome and value of the research**

The results were expected to establish:

- Which aspects of incontinence were important to patients
- What women expected from surgical treatment
- Whether or not these expectations were being met by surgical treatment

- Those areas that were not met by current management of incontinence

It was anticipated that this research would form the basis for a screening tool providing construct and content validity. Unmet patients' expectations may need addressed in preoperative counselling. Manageable aspects of incontinence not currently addressed can be tackled in the future. Other modes of incontinence treatment, such as medical and behavioural therapies, could be investigated in a similar way in the future leading to a screening tool to apply to patients before treatment to determine which course of treatment they are most likely to benefit from. Psychological factors may need to be addressed in patients presenting with UI.

6.3 Ethics

The research proposal (see Appendix I) was peer reviewed externally and approved by the BWH Research and Development Department. The COREC (central office for research ethics committees) application was submitted and ethical approval was granted from the Solihull Local Research Ethics Committee (LREC) after a face-to-face meeting with the primary researcher. Site-specific approval was then granted from the South Birmingham LREC. The ethics process is rigorous attending to widespread aspects of this research. Examples are shown in Table 6.2.

Table 6.2 Ethics examples

Ethical issue	**Response**
Consent	Informed consent was obtained by the primary researcher. This was written and in the format recommended by COREC. The primary researcher was accustomed to obtaining consent. A basic consent

	form was devised for participants to complete prior to any pilot interviewing (Appendix II). A patient information leaflet and consent form was later developed and used in accordance with COREC recommendations (Appendix III)
Privacy	Interviews would take place in private in outpatient consulting rooms or on the ward. Urodynamic facilities are already available in the unit with appropriate changing facilities and chaperoning
Information	The consent form included information on the study. The primary researcher was also given as the point of contact if further information was requested by participants
Complaints	Any research participants who wished to make a complaint could contact the primary researcher or avail of the hospital's Patient Advocate Liaison Service (PALS)
Extra support	If participants required extra support as a result of their participation they could receive follow up in the outpatient department or referral to their GP or other specialist as appropriate
Payment	Subjects did not receive any payment for taking part. The researcher did not receive any payment other than a salary
Confidentiality	Published and presented data included some direct quotations but the identity of the participants remained confidential
Scientific quality	The research proposal was peer reviewed externally and by both advisory supervisors. It was also reviewed by the hospital research and development committee and on submission to the university at registration
Funding	The project was funded by the hospital urogynaecology research fund
Exclusion criteria	- Women who do not wish to participate - Men

	- People who were not able to articulate themselves or read or have a good understanding of English

- Ethical problems

1. Some participants experienced emotional upset when discussing things of a personal and bothersome nature. They were advised before the interview that they may stop at any time. Interviews were conducted in a sympathetic manner and with no upper time limit if the participant wished to discuss things further. If the participant wanted further help or support then a referral could be arranged directly or via the GP
2. The research methodology of this phase of the study was only suitable for articulate women capable of understanding and speaking English. It is recognised that other excluded parties are likely to have relevant information and it may be possible to include them in further phases of the study

6.4 Evolution of the methodology

Where possible the original planned methods were followed. During the course of the interviews it became clear that some subjects used repeated themes in their repertory grids or struggled to formulate constructs and for these subjects the free flowing interview gathered useful additional information. The pilot phase of the study acted as action research allowing refinement of the methodology and formulation of a more robust research protocol. The pilot patients were included in the first patient group. Subjects for all three study groups (Table 1.1) were exposed to qualitative

interviews and repertory grids but additional measures were applied to Group 3. The separate groups were not formed to be comparable, as in a randomised controlled trial (RCT). Rather they allowed an enhanced focus on the subject area. The first group was used to gather a broad general overview of the subject matter and all treatments of UI. The second group had all been exposed to surgical treatment of SUI and this enhanced the focus to allow development of the third group methodology. The third group were due to undergo SUI surgery and this was the main opportunity for studying the crucial aspects of what changes before and after surgery and allowed subjective and objective measures of cure to be made.

Written consent was obtained before the interactions within the project. All subjects knew that they were participating of their free will and could terminate the interview at any time, without compromise to their treatment. A chaperone was not used for the interviews (with the exception of urodynamic studies) as the presence of a third party was felt to be potentially detrimental to full information gathering. Additionally, given the long duration of interviews (up to two hours) a chaperone was not practical or possible within the constraints of the project. The interviews comprised a combination of repertory grids, free flowing interviews, visual analogue scales (VAS), brief questions and urodynamics for various patient groups.

The researcher recorded interviews in immense detail, by hand. This is quite different to a usual consultation in which note taking is kept brief and seemingly relevant. All items were recorded including observations and actual words said (including grammatical errors). This is very important, as non-verbal cues are as important as

what is actually said. Audi-taping of interviews was not performed, partly because of lack of resources and skill to transcribe from tape to the written form for analysis. Furthermore, audiotaping would not capture the non-verbal cues. The presence of a tape-recorder (or video-recorder) may appear intrusive and impair subjects' willingness to open-up. The actual language used by the patients may give an indication of whether or not they have a full understanding of their situation, condition and treatments. An example would be that patients often say that they had a 'bladder repair'. They are therefore often disappointed that they have bladder problems following this. The term 'bladder repair' is commonly used by laypeople to describe 'anterior vaginal repair'. This operation fixes a bulge in the front wall of the vagina and therefore adjacent to the bladder. It does little to help the bladder function and can even cause or worsen bladder problems. This is an example of why noting inaccurate or incorrect language may go part way to explaining why someone is feeling the way they do about previous treatments.

The repertory grid technique was initially the main methodology and interviews were conducted to back these up. As the interview process progressed the importance of the free flowing interviews became more obvious with an increasing emphasis on these. There were slight changes in the construction of the grids and how these were performed. Most of the changes occurred during the action research pilot phase (Chapter 10) and otherwise changes were just in tense to take account of what stage of treatment subjects were at. Fixed psychometric measures like questionnaires need to be reliable and valid. This differs from interviews and repertory grids, which are designed to be changeable and capture individual information. The KHQ is used,

which is a validated questionnaire but this lacks the depth and breadth required to explore the patient experience. The pilot stage established the repertory grid technique to be a workable methodology (Chapter 10). Repertory grids do not have a fixed protocol and they can be adapted to suit the purpose of the study. The repertory grid technique was used and the format evolved through the pilot stage of the study (Chapter 10).

6.5 Repertory grid technique

Repertory grids are discussed more fully in Chapter 7. There are various ways to interpret and illustrate the results of repertory grids. Initially it was decided to use a semantic analysis of the grid contents using Roget's Thesaurus. This was performed by looking up every term in the grid in Roget's thesaurus by hand to classify the words used. These were then put into groups. It became obvious during this analysis that this was not particularly useful because of some of the language used and overlapping meanings and duplications. For example, if someone uses the construct 'not able to go out/able to go out' this was classified in Roget's Thesaurus as 'egress'. If someone forms the construct 'leakage/no leakage', when referring to UI, this was also classified as 'egress'. Both of these constructs have completely different meanings and therefore for them to be classified together is nonsense.

Despite a time-consuming analysis of several grids in this manner it was decided to cease this as a form of analysis. Thereafter the bipolar constructs were hand-sorted according to common meanings. Leakage, incontinence, wet and damp were therefore classified together to have one meaning. On the other hand, going out,

restricted and not able to travel may be classified together. Each construct was hand written onto a record card. These were then hand sorted into categories of similar meaning. Some cards appeared in more than one category. Thematic analysis of the meanings was then performed. The methods used for thematic analysis of both the bipolar constructs and the interview text used the same basic method[94]. After the meanings were abstracted from the constructs, the constructs were then reread to ensure they had been grouped correctly into themes. Themes were then refined so that they were broad enough to encapsulate the ideas in the construct or text segments but specific enough to be non repetitive. The data then became a manageable set of themes summarising the grid or text. As the themes emerged they had to be moulded to accommodate new text segments.

The thematic analysis was represented as thematic networks summarizing the main themes in a piece of text[94]. This method allowed all of the text to be analysed and also had the advantage of permitting text segments to appear in more than one theme. An example of this is if a woman said 'I am worried about being wet' this may have been grouped together with other statements about 'worry' and statements about being 'wet'. Table 6.3 illustrates theme order.

Table 6.3 Levels of themes in a thematic network

Stage of thematic network	Description
Basic theme	The lowest order
Organizing theme	Derived from grouping similar basic themes together

Global themes	Super-ordinate themes grouping organised themes together

In light of the basic themes, the main claim, proposition or argument becomes the global theme. Each global theme is at the core of a thematic network. A set of themes may well yield more than one global theme. Once organising themes have been formed they are reinterpreted in light of the basic themes. Thematic networks serve as an organising principle and illustrative tool in the interpretation of the text. After the thematic networks were created, they were explored and described. Thematic networks are a tool in analysis rather than the analysis itself. The themes were explored and underlying patterns developed. To describe the network the contents were described and illustrated with text segments. The original research question was then addressed with arguments based on patterns emerging from exploration of the text.

6.6 Qualitative interviews

Qualitative interviews were performed in all three patient groups in this study. Interviews were useful to provide rich individualised data. They are ideal for studying particular areas such as thought, opinions and attitudes where there is not a limited set of fixed responses. They allow the freedom for the participant to bring up new concepts and freedom for the researcher to explore these. Disadvantages of the interview process include a possible lack of standardisation resulting in challenges in grouping responses together and consequent challenges in analysis. Recording the data and handling the large amount of text can be overwhelming. The interaction

between the interviewer and the participant can affect the findings. The interviewer may have an undesirable influence on the direction of the interview or how open the subject is. The participant may feel less anonymous or may be more reluctant to answer personal questions than they would be answering a written questionnaire. In this study interviews were initially used as back up to the repertory grids but it soon became obvious that they were valuable in their own rite in providing answers to the research questions of the study. Berglund recognised the importance of interviewing techniques in operative candidates for SUI and suggested that qualitative methods are sought for looking at SUI as social restrictions had been identified[95].

In this study interviews were prospective in the third group who were due to undergo SUI surgery. The other two groups (1 and 2) were mainly retrospective, reflecting on the past but also were able to discuss their present condition and the future. Dillon says:

'If you have to ask too many questions, they are not the right ones. Prepare dummy answers to some of your questions beforehand and see if they form the sort of knowledge wanted. Dummy answers are clever, they can tell us what we want to know and how to ask for it, so, make a dummy out of the answer before the answer makes a dummy out of you'[96].

The interviews sometimes went off at a tangent and this was permitted. The subjects were encouraged to talk freely with the minimum of prompting. If they stopped speaking then they were prompted with open statements such as:

- Then what happened?
- How did you find that?
- How did that make you feel?
- What else?

The interviews were recorded verbatim, in writing, during the interview. These were typed soon after the interview had concluded. Writing while conducting an interview was challenging but became easier with practice. Each interview underwent thematic analysis by breaking down every statement into text segments and writing each onto a record card. These cards were then rearranged undergoing thematic analysis by recognised methods[94].

Group 3, interviewed before and after SUI surgery, each had a list compiled of things that they had mentioned in their preoperative interview. This list was then posed to them at the end of their postoperative interview. Many of the factors may have already been mentioned but if they were not then this was an opportunity to clarify whether or not they had been modified since their surgery.

6.7 Visual analogue scales (VAS) and additional measures

Those patients who were seen before and after their SUI surgery were also given a VAS to complete as an additional subjective outcome measure. Very simple phrases were used to try to gauge subjectively how they felt about the success of their operation, their satisfaction and their leakage. Additional questions about how relaxed or tense and happy or not happy were included. The subjects were asked to rate the items on the 10cm horizontal ruled line, which had 0 at the left hand side and

10 at the right hand side. The questions were labelled with the more favourable outcome to the right with the exception on the fifth question where the more favourable question was on the left. This was done in the hope that the women would read and think about their responses rather than putting all their marks at a similar place on each line.

Question 1)

Mark below on a scale of 0 to 10 how successful do you feel your operation has been? 0= not successful 10= completely successful

Question 2)

Mark below on a scale of 0 to 10 how satisfied you are with the out come of your operation 0= not satisfied at all 10= completely satisfied

Question 3)

Mark below on a scale of 0 to 10 how happy you feel at the moment

0= very unhappy 10= very happy

Question 4)

Mark below on a scale of 0 to 10 how relaxed you feel at the moment

0= very relaxed 10= very tense

Question 5)

Mark below on a scale of 0 to 10 how much urinary leakage you suffer now

0=leak all the time 10= never leak

The subject was then asked to self-complete the following:

Situations affected by incontinence

Please list five situations were your incontinence causes you the most difficulties

1.

2.

3.

4.

5.

Please list five situations were your incontinence is less of a problem to you

1.

2

3.

4.

5.

Do you wear pads or any extra protection? YES / NO

If yes, what sort of pads do you use?

How many a day do you use?

Why do you wear them?

6.8 The Kings Health Questionnaire (KHQ)

The KHQ was only used for Group 3 who underwent evaluation before and after SUI surgery. The KHQ is a UK devised validated continence specific QoL tool. It was used as a recognised outcome tool in addition to the VAS, urodynamics, repertory grids and interviews (Appendix V).

6.9 Urodynamics

Urodynamics were performed preoperatively only for the third group of patients who were interviewed before and after surgery for SUI. It was routine practice in the unit to perform preoperative urodynamics on everyone undergoing SUI surgery. Postoperatively urodynamics was performed, by the researcher, as an objective measure of cure for the purposes of studying these cases in detail.

6.10 Analysis and interpretation of data

The data collected through grids and interviews were analysed by thematic analysis[94]. Themes from literature and the focus group were added to this information. The group of patients who were interviewed preoperatively and postoperatively (Group 3) had their interviews, repertory grids and additional measures scrutinised to see what had and had not changed since their operation. It is recognised that every subject's experience is relevant and valid and therefore the strength of constructs was not analysed, rather the themes and relationships between elements and constructs.

6.11 A critique of the research methods used

6.11.1 Electronic literature searches

The literature searches in this study were used to identify themes related to UI and also to identify other work relating to this area of study. This is presented in Chapter 8. Information gained from the literature was analysed by a process of distillation of the information into themes. The four main steps of literature searching in evidence based medicine are[97]:

1. Formulate a clear clinical question from a patient's problem
2. Search the literature for relevant clinical articles
3. Evaluate (critically appraise) the evidence for its validity and usefulness
4. Implement useful findings in clinical practice[97]

There are various methods available to analyse literature and in this study a narrative approach was used. Data analysis has advantages and disadvantages when compared to other methods, particularly the systematic review[98]. The systematic review is seen as the gold standard method to analyse literature. Narrative reviews involve a general discussion of a topic area and provide no justification for the inclusion or exclusion of given studies. Differences in study methodologies or quality are overlooked. When drawing conclusions, narrative reviews fail to differentiate between good and poor studies and conclusions can be subjective[98].

In contrast, systematic reviews specifiy a clear question to be answered by the review and attempt to include all published and unpublished studies. They are explicit about inclusion and exclusion criteria and use a rigorous protocol for assessing the

quality of studies to be reviewed. Systematic reviews are relatively unbiased and objective, basing the conclusions on the best quality studies[98].

Evidence can be graded according to the methodology through which it was obtained. There are various systems available and generally there are four categories with the first being classified as the strongest level of evidence. The system used by the Royal College of Obstetricians and Gynaecologists (RCOG) in the development of their clinical guidelines is shown in Table 6.4.

Table 6.4 RCOG Classification of evidence levels[99]

Class	Description
Ia	Evidence obtained from meta-analysis of randomised controlled trials
Ib	Evidence obtained from at least one randomised controlled trial
IIa	Evidence obtained from at least one well-designed controlled study without randomisation
IIb	Evidence obtained from at least one other type of well-designed quasi-experimental study
III	Evidence obtained from well-designed, non-experimental, descriptive studies, such as comparative studies, correlation studies and case studies
IV	Evidence obtained from expert committee reports or opinions and/or clinical experience of respected authorities

The place of qualitative studies in medical literature and the strength of qualitative evidence is debated[100]. It is virtually overlooked in Table 6.4 and qualitative work

would not be likely to obtain a rating above class III. While qualitative work studies areas not amenable to RCTs it is possible that health professionals are leaving important areas and aspects of healthcare unstudied or at least unreported.

While narrative reviews carry the problems of bias and lack of objectivity, they do provide a richness of data that systematic reviews do not afford. A systematic review would not have been relevant in this study because the aim was to gather literature on work done to date in particular areas relatved to the research objectives rather than to answer a question about effectiveness of a particular intervention.

A narrative review was the most suitable method of literature review in this study because:

- There is little or no consistency between methods used in the literature in this area
- If a rigorous protocol was used to include/exclude papers then valuable information and themes may have been overlooked
- Alternative review processes, such as the gold standard systematic review, would have been inappropriate as there is not a treatment effect being evaluated

The chosen method of thematic analysis[94] was the most suitable because:

- There is a clear structured protocol to follow[94]
- No specialist equipment is required and using hand sorted record cards means that the meanings of phrases can be checked during sorting rather than

possible confusion over meanings as could occur by computer assisted analysis

- The method also allows phrases, statements and constructs to appear in multiple categories of themes
- The protocol encourages the emergence of themes throughout the process
- The method allows the production of thematic networks around which theories evolve

6.11.2 Focus Groups

Focus groups are very flexible and can be used to study a great variety of areas in the social sciences and market research. They are an exercise in group dynamics and therefore the interpretation of the results must be understood in the context of group interaction[101]. Focus groups are particularly suited to situations where the nature of enquiry is exploratory. There may be some bias depending on psychological, social, cultural and environmental influences. Many researchers rely on volunteers, which may also bias the findings[97]. The usefulness and validity of results from focus groups depends largely on the extent to which participants feel comfortable about openly communicating their ideas, opinions and feelings. These influences can be grouped into intrapersonal factors, individual differences, interpersonal factors and environmental factors[101]. Diversity within the focus group can be both an advantage and a disadvantage. Diversity provides greater perspective and innovation but greater heterogeneity is associated with less communication among members and possible conflict[101]. Group dynamics can also be affected by age, gender and personality. An additional advantage of the

methodology is that is does not discriminate against people who cannot read or write. Participation from people reluctant to be interviewed on their own or who feel they have nothing to say can be encouraged in the group setting[102]. Focus groups do not just find out what people think but also how they think and why they think in a certain way. The dynamics between participants adds a dimension not present in individual one-to-one interviews. They are particularly useful to examine people's experiences of disease and of health services, such as in this study. They are also useful to explore needs and attitudes of staff.

Focus groups should be distinguished from groups whose primary purpose is something other than research. Alternative purposes include therapy, decision making, education, organizing or behaviour change[103]. Focus groups should also be distinguished from other procedures with multiple participants but without interactive discussions such as nominal groups. Group discussions that are naturally occurring and where no one acts as an interviewer/moderator are also distinct from focus groups. Results obtained from focus groups have been compared to other methods[103]. When compared to surveys the results from focus groups have been found to be similar and would lead to the same conclusions but the focus group provides more information on many of the variables studied and provides deeper understanding[103]. While this convergence of topics is useful there are also some differences. Surveys can force 'yes/no' answers where focus groups do not. A 'yes/no' answer is easier to manage and gets an absolute answer to a question. This forced choice response, however, limits what respondents can say on general attitude areas as opposed to more open questioning in focus groups. Surveys

generally cover many more topics than focus groups and there is therefore a trade off between breadth and depth of questionning[103]. Individual interviews can be more effective for idea generation and surveys can be more effective for determining the prevalence of any particular attitude or experience. The real strength of focus groups is providing insights into the sources of complex behaviours and motivations. This results from the group effect where participants query each other and explain themselves to each other. The ability to observe the nature and extent of participants' agreement or disagreement is a unique strength of focus groups[103].

Weaknesses of focus groups are linked to the role of the interviewer/moderator and the impact of the group on the data[103]. It is suggested that the control exercised by the moderator inhibits some of the natural conversational elements present in non focus group discussions. It is possible the participation in a focus group can actually change the participants' views and work previously done suggests that views may become more polarized and extreme[103]. Because group interaction requires self-disclosure it may not be acceptable to discuss all topics in this environment. This study suggests that UI, a highly personal topic, was openly discussed in the focus group setting. The emphasis was, however, on the service rather then each individual's experience of UI itself.

Focus groups allow a variety of views to be expressed and the participants can determine the direction of discussion topics. Like the repertory grid everyone's views are valid although the group dynamics may affect the expression of these. A minority view may not be expressed depending on the dynamics of the group. There may be

a tendency for people to agree with each other as a social nicety rather than it being their actual opinion. There can be a social hierarchy where some people feel more able to speak than others. In this study the focus group was seen as a complementary methodology to use in combination with other methods of data collection.

The focus group was an appropriate method in this study because:

- It allowed for the development of themes amongst participants that may not occur in the one-to-one interviews
- It allowed for participation of people who would not feel comfortable in a one-to-one interview
- People who feel that they do not have much to say may find themselves able to contribute in a focus group setting
- Group dynamics can be observed not present in other methods
- Subjects will be examined in more depth than other methods such as questionnaires
- The results were complementary to other methods used in this study, adding content validity to any future tool developed

6.11.3 The repertory grid technique

The repertory grid technique is the central research methodology used in this study and has been described and critiqued extensively elsewhere in this thesis. In Section 5.3 the repertory grid's place in the context of qualitative and quantitative research is explained and comparisons made with other methodologies such as the RCT. The

analysis, interpretation and illustration of results obtained from repertory grids are discussed in Section 6.5. The Theory of Personal Constructs as described by George Kelly[104;105] is presented in Section 7.2. Components of the repertory grid are explained and their relevance within personal construct psychology (PCP). Methods of performing and analysing repertory grids are discussed and examples of previous work using repertory grids are given. Section 7.3 describes features of the repertory grid technique and compares the method to other measures and psychological tests. Advantages and disadvantages of the technique are discussed and uses of the repertory grid are presented.

The key advantages of the repertory grid technique follow[106-113].

- Its ability to capture information of an individual nature
- Suitability for studying interventions (or treatments) of a multifactorial nature
- Suitability for studying opinion
- Suitability for studying the unknown where preset answers are not desirable and the aim is to discover new information
- In depth study of subjects
- Small sample sizes
- Amenable to analysis by various methods
- Allows a clinician to engage with a patient using the patient's frame of reference rather than being imposed by the clinician; this allows better understanding of the patient
- Wide ranging applications such as psychology, education and market research
- Data rich results

- The technique can be modified to suit the needs of the user
- Studies an individual's microcosm rather than measuring an individual on a set scale
- As an opaque measure it may be used to study topics indirectly thus preventing the individual from intentionally distorting responses
- It does not presume that interviewer and subject attach the same verbal labels to things
- The technique should not be effected by intelligence, age or gender
- It can be used to test hypotheses
- It avoids asking direct questions and is therefore useful for a potentially embarrassing area of study
- It avoids presumptions by the researcher
- It allows new factors to emerge
- Although considered qualitative, it can be scored and therefore is also quantitative and amenable to statistical analysis

The disadvantages of the repertory grid technique are summarised below.

- It is not considered a high level of evidence within evidence based medicine
- There is no comparable control group
- Results may be ungeneralisable
- Some people have difficulty working with supplied constructs
- Considerable time and effort are required to perform repertory grids
- Some people may have difficulty articulating constructs
- The technique does not lend itself to comparing people

- The researcher and subject need to speak the same language
- Analysis and interpretation are required. There is no instant score or result such as may be obtained with questionnaires
- The accuracy of data may be lost in summary of thematic analysis of results when detail may be lost

The qualities of the repertory grid make it highly suitable for this study of UI[3]. The potentially embarrassing nature of UI makes this opaque method of enquiry very desirable, while the ability to use the subjects terms of reference and allow the subject to select what factors matter to them are central to the study's aims. There are many questionnaires available to place people on a scale relating to quality of life or psychometric factors[114] but these would allow nothing new to emerge. Chapter 10 includes a description of the evolution of the theoretical repertory grid into a workable protocol for this study through action research with the pilot group.

6.11.4 Qualitative interviews

Interviews are one type of qualitative research methodology and it has been suggested that qualitative methods should be used to study surgical areas in relation to social aspects of care[115]. Interviews are able to obtain highly personal, individualised, experiential information not amenable to higher-rated quantitative methods such as RCTs. With interviews it is possible to explore social factors and get opinions revealing reasons behind issues such as thoughts, choices and attitudes. Small sample sizes are appropriate to explore subjective matter in depth during individual interviews. Subjects have a degree of freedom and can bring up new topics

and ideas and there is the opportunity in the interview setting to further explore issues at the time.

There are, however, weaknesses and challenges with interviews. There can be a large volume of data to record and handle. Recording the interview can be a challenge. Video or audio methods can appear intrusive but do allow accurate recording that can be verified by a third party. Tape recording may make respondents anxious and less likely to reveal confidential information[90]. Tapes take a long time to transcribe and analyse[90]. Note-taking can be challenging but is less intrusive, requires no specialist equipment and gives an instant record of an interview[90]. Non-verbal cues are important and these can be missed with certain methods of recording. As there are no set responses with interviews it can be more difficult to group ideas and responses together. The attempt to summarise and distill results down to a useful summary can result in loss of detailed, individual information that the interview is so good at collecting in the first place. Interviews are time consuming and not as easy to administer as questionnaires. Interviews are less anonymous and so participants may choose to conceal things they feel are too personal or embarrassing. More may be revealed in a questionnaire than face-to-face although the depth and reason behind a questionnaire response cannot be fully explored. The interviewer can impose his/her values on the analysis and can lead the responses, thereby increasing the risk of bias.

Interviews vary in the degree to which they are structured or unstructured, formal or informal, focused or open and so on. The term ‘qualitative interview’ is a broad term

to denote a family of interviews that share the common purpose of studying phenomena from the perspective of the respondent[97]. If unstructured it should resemble everyday conversation but the degree of structure and control vary from interview to interview[97]. Chapter 10 describes the development of the research interview protocol, through a series of pilot interviews, into a workable methodology. Interviews are very useful for collecting data which would probably not be accessible using techniques such as observation or questionnaires[90]. They are therefore highly suitable to obtain the detailed, personalised accounts required for this study and have been used in previous studies in the field of UI[25;27;116-118] as outlined in Appendix VIII.

Interviews are discussed in detail at various points throughout this thesis. In Section 5.3 the value of qualitative research is discussed and a comparison made with quantitative research. Table 5.1 illustrates the main differences between qualitative and quantitative research. There is a particular focus on comparison with the RCT because it is seen as the gold standard in evidence based medicine. However, the RCT is wholly inadequate at measuring in depth experiences and qualitative approaches are therefore indicated. In Section 6.4 the usefulness and value of the qualitative interview method is discussed. Section 6.6 outlines advantages and disadvantages of interviews. The analysis of the data obtained through the interview process is described in Section 6.10. Thematic analsysis is used to analyse the interviews and this is critiqued in Section 6.11.5.

6.11.5 **Thematic analysis**

Thematic analysis was used at various points in the study for the identification of themes from the literature, focus group, repertory grids and qualitative interviews. Grounded theory is the conceptual framework for thematic analysis and in this study a systematic approach to data analysis was used[94]. The strength of grounded theory is that it allows researchers to start afresh and not be influenced by present knowledge, thereby opening up the possibilities of new perspectives on old problems[97]. Grounded theory studies phenomena from the viewpoint of the subjects and relies on data to formulate hypothesis and theories. Tasks in grounded theory are organising information, identifying patterns, developing ideas, and drawing conclusions. Emerging hypotheses are constantly reviewed during data collection[97]. Rather than generating hypotheses and then collecting data to establish whether or not the hypothesis has been supported, grounded theory starts off with the information from which hypotheses and theories emerge[119]. It is an authentic open means of achieving a comprehensive description of given situations or events followed by the formulation of a theory or set of theories[89]. Once the enquiry no longer yields new information the researcher's enquiry reaches saturation[89]. The approach is systematic and theories are based on rich accounts of real life experiences[89]. Grounded theory is a popular method used in a variety of settings, not restricted to healthcare, with a focus on functional explanations and lived natural experiences.

Disadvantages with grounded theory include the possibility of bias. Bias can be present if a researcher focuses on particular aspects of the phenomenon rather than others. There may also be bias in the selection of respondents and in the analysis of

data[97]. Care must be taken that comments are not lifted or quoted outside of their context as conclusions arrived at under such conditions can be premature and misleading[90]. The investigator's values and prior theories may influence the kind of theory that is generated[89]. It has been suggested that the researcher's values and position should be made explicit, however, researchers may not themselves be aware of their own presuppositions[89]. Findings from thematic analyses may not be generalizable and are not usually expressed in statistical terms.

Various methods of thematic analysis and grounded theory are prevalent in the literature[26;117]. In this study a rigorous systematic protocol of thematic analysis was adopted as published by Attride-Sterling[94]. This method has been well described and attempts to be very systematic to avoid bias. The formulation of thematic networks is described in Section 6.5 and Table 6.3. Section 11.2 describes how the analysis is performed for results from the repertory grids. Results of thematic analysis by this method are represented in thematic networks. Numerous thematic networks are included in this thesis and Table 11.2 is just one example.

Alternatives to this method involve coding of data either by hand or computer. In this study the actual meaning of data was used to sort into categories. Basic, organising and global themes then emerged. Computer based analysis can be used, however, there was concern that this would use words rather than meanings. This approach led to errors in one analysis that was abandoned as discussed in Section 6.5. Analysis can be performed directly from interview transcripts[90] rather than by writing

onto record cards as was performed in this study. Verifying thematic networks with other observers may have strengthened the results of this study.

6.11.6 Visual analogue scale

Visual analogue scales (VAS) are easy to administer and simple for the subject to understand. They are in common use and were used in some studies included in the literature search of this study[11;120]. The VAS is a simple and quick method. It is easy to complete by subjects who simply read the question and place a mark on a line. No specialised equipment is required to set up, use or interpret a VAS and results are understandable at a glance. The ease of completion and interpretation is partially because of the pictorial representation of the line. A score is easily assigned (by measuring the length of the line) and therefore results are also amenable to statistical manipulation. The language is uncomplicated and the scale takes little time to complete[97]. It can chart changes over time and is useful at measuring change within individuals. It is a very versatile and valuable approach to data collection and can be modified to suit many research questions[119]. The VAS is useful in clinical practice as well as in research and is commonly used to measure pain. It can be administered quickly and easily and is suitable for most populations making it ideal in the clinical setting.

While the VAS is very useful there are some disadvantages. People with visual impairment or psychomotor disability may find it difficult to make their mark on the line[97]. Too much can be read into the numerical scores and rank ordering may sometimes be more useful. There are ongoing debates as to whether data is ratio or

ordinal[119]. The information gained is global and there is no subtlety or depth. It tells us nothing about why someone has given a particular response. The nature of the VAS is that only set questions are responded to. While this makes the method very user friendly it allows for nothing new to emerge. It is simplistic and an unsuitable method for exploring issues. It was very useful in this study to globally find out if subjects thought they were cured, satisfied, happy etc. In addition it is not clear what result is significant or meaningful.

There are alternatives to the VAS. The semantic differential scale can also measure an attitude or feeling towards a concept or phenomenon[97]. It has a stem, steps and anchors. The stem is that which is being measured and the anchors are the extreme ends of the scale with the steps as the gradations to choose from. There can be five to nine steps and scores are read off the scale and are amenable to statistical analysis. The VAS allows more freedom because the line is an unmarked continuum[97]. Rating scales are another alternative and are made up of statements or items that respondents are required to rate. Each rated statement is given a score and the total score is given an interpretation[97]. A Likert attitude scale uses a five point scale ranging from ‘strongly agree’ to ‘strongly disagree’ through ‘don’t know’ to respond to a series of statements[97]. These methods are all types of questionnaires, however, rating scales use summed responses. In contrast most questionnaires contain a set of questions mostly in closed and open ended formats and responses to each question are treated on their own and analysed separately. Together responses from all the questions provide an answer to the research question or hypothesis[97].

The VAS used in this study is described and discussed in Sections 5.3, 6.7 and 13.4. The purpose was to try to sort subjects into cured and not cured by a subjective measure- the VAS- using leakage, success and satisfaction as illustrated in Table 13.4. Other measures of cure were included and compared to results by VAS. The VAS scale was chosen as an additional method alongside a QoL questionnaire, interviews, repertory grids and objective testing in the form of urodynamics. Sections 13.5 and 13.6 discuss the results including the VAS and the challenges of defining cure. Section 14.5 shows a 1-way ANOVA using the VAS results. The scores were treated as ratio data for this purpose and showed a significant variation between the women studied but not between the measures on the VASs.

6.11.7 Kings Health Questionnaire

A questionnaire can be described as a method that seeks written or verbal responses from people to a written set of questions or statements[97]. The Kings Health Questionnaire (KHQ) is a recognised, psychometrically validated, disease-specific quality of life tool and is used widely both in clinical practice and research[21;80;121;122]. It contains several domains, namely, general health perceptions, incontinence impact, role limitations, physical limitations, social limitations, personal relationships, emotions, sleep/energy and severity measures. This appears to capture a wide range of QoL issues and was therefore well suited to this study. QoL tools are often used in research including the Short Form 36[122-124] and the I-QOL[19]. NICE recommends the KHQ as well as other QoL scales when therapies are being evaluated. It is freely available through the NICE[38]. Other recommended scales include the Bristol Female

Lower Urinary Tract Symptoms questionnaire (BFLUTS), the International Consultation on Incontinence Questionnaire (ICIQ) and the Incontinence Quality of Life questionnaire (I-QOL). Questionnaires are one of the most commonly used methods of data collection in social and health research and are often used in clinical practice to collect diagnostic and demographic information[97]. Questionnaires have the advantage of being flexible in their administration with options including face-to-face, through the post or internet. Face-to-face is more time consuming while other methods may lead to reduced response rates but do allow respondents to answer in their own time and at their own convenience[90;97]. Telephone surveys are also popular in health and social sciences and market research[97].

There are different ways of asking questions in questionnaires such as quantity, category, multiple choice, scale, ranking and open ended. Wording is important and piloting can help to refine a questionnaire[90]. By using a previously tested and validated questionnaire, such as the KHQ, these issues have already been tested and resolved. The questionnaire is potentially quick and cheap, relatively confidential and frequently anonymous. It is able to collect large amounts of information from a large number of people over wide geographical areas. Questionnaires have a fair degree of reliability and comparisons between respondents can be made as data is collected in the same form[97]. Researchers must choose the most appropriate data collection method to answer their research question[97]. Closed questions include two-way questions, checklists, multiple choice questions and ranking scales. Closed questions are asked when the researcher considers that they know all the potential answers. This is the reason why this method was not the main one chosen for this

study as it was anticipated that new issues would emerge and therefore qualitative repertory grids and interviews were the main methods[97]. Open-ended questions allow for new things to emerge and have been described as easy to ask, difficult to answer and even more difficult to analyse. An open ended question must be clear and unambiguous or different respondents will interpret it differently[97]. What people say and what they mean may not be the same and with a questionnaire there is not the opportunity to unravel this. This is where interviews are superior. Data from questionnaires may be qualitative or quantitative. Closed questions and rating scales can be precoded and therefore easily and quickly analysed sometimes using computerised packages[97]. Self administered questionnaires have the advantage of the absence of the interviewer effect while telephone questionnaires may be a compromise[97].

The main disadvantage of the self administered questionnaire is that there is no opportunity to ask respondents to elaborate, expand, clarify or illustrate their answers and respondents themselves have no opportunity to ask for clarification[97]. Questionnaires tell us little about the context of the responders answers and data can be superficial and separate the measured behaviour from the historical, social and cultural contexts[97]. Questionnaires do not suit those who have difficulty in reading and comprehension and in articulating written responses. Some may ask others to complete their questionnaire for them making responses less reliable. Response rates can be poor as questionnaire completion can be seen as a burden or additional paperwork. There is also sometimes a presumed hardship entailed in being a survey participant known as ‘respondent burden’[97].

The KHQ was rigorously developed in the UK and based on interviews and item reduction. The instructions to participants are clear and it is quick and easy to complete. It is in use in many clinical and research settings and is available for use in many languages, which was not required for this study but could be useful in further phases. There is a marking system so that scores are assigned to each domain for each participant and this is shown in Appendix V. Questionnaire based data is easier to handle than qualitative data as it can be more easily reduced. All subjects are asked the same questions making data handling easier. This reductionist approach is consequently closed as it uses a fixed set of questions. It is not in any way exploratory and does not explore any thoughts or feelings behind the responses.

The KHQ was used as one of several outcome measures to study a group of women undergoing SUI surgery. In Sections 5.3 and 6.8 the use of the KHQ is discussed in the context of the study's methodology. The use of QoL life tools, including the KHQ, is discussed in Section 8.3 and the use of the KHQ in this study is described in Section 13.2. A Venn diagram of themes captured by different methods in the study, including the KHQ, is represented in Section 14.2. Very little overlap in themes, derived from the KHQ and other methods, suggests that the KHQ may fall short of capturing the full range of patient experiences of UI. A related 't' test was performed to see if KHQ scores are significantly different before and after SUI surgery and this is discussed in Section 14.4. There was a significant difference of total scores before and after SUI surgery suggesting an improvement on this measure but as discussed the KHQ is not designed to be used in this way.

The KHQ was chosen for this study because:

- It is easy for subjects to use[121]
- It is recommended by NICE[38]
- It has proven validity evaluating QoL in women with UI[121]
- It may be used in clinical as well as research settings[121]
- It was developed with a UK population
- It is available in many languages should further phases of research require this
- It can be analysed from paper completed forms and therefore does not require specialised equipment or computer packages
- It is free to use and analyse
- It is easily incorporated into clinical practice at little expense

6.11.8 Urodynamics

In this study the term 'urodynamics' refers to dual channel subtracted cystometry. Urodynamic studies are performed in the UK as part of clinical practice to clarify the clinical picture and guide treatment and this is discussed further in Section 3.6. The experience of urodynamics is discussed in many of the qualitative interviews as can be seen in Table 12.2. One group of subjects in this study (Group 3) had urodynamics performed as part of their clinical care in their work up for USI surgery. In clinical practice urodynamic traces are printed and retained in patient records for further reference and were therefore available to the researcher without the need to repeat urodynamics preoperatively. Postoperative urodynamics is not routine and was performed as part of this study as an objective measure of cure. Urodynamic

studies were used together with other outcome measures (VAS, KHQ, repertory grids and interviews) in order to triangulate the data and Table 13.1 outlines the research protocol including the place of urodynamics. The aim was to enable detailed study of cured/not cured and satisfied/not satisfied participants and this is discussed further in Section 6.9. The results shown in Table 13.3 include urodynamic findings as one way to define cure by the presence or absence of USI.

In Section 13.4 the use of urodynamics in this study is described along with other methods. The use of urodynamics in clinical practice is controversial but it is accepted as the gold standard for studying functional aspects of the bladder and diagnosing urodynamic stress incontinence and detrusor overactivity. It is accepted as a superior method to alternative objective testing such as pad tests[38]. Ambulatory urodynamics and videourodynamics may add some additional information but are not routinely recommend[38]. Controversy surrounds the test-retest findings and the discordance between findings on urodynamics and the clinical picture. The test can be embarrassing and uncomfortable and uses health resources and these factors must be balanced against its clinical relevance. In the absence of a better test it is commonly performed for select cases, most commonly prior to SUI surgery. The objective finding of a condition may not relate to the amount of bother experienced by subjects and this is another weakness with the test. In the absence of a better objective test it was used in this study. Many other researchers have used it as the gold standard objective test or to group subjects before measuring other factors[21;114;120;125-128].

CHAPTER 7

PERSONALITY THEORIES, PERSONAL CONSTRUCT PSYCHOLOGY AND THE REPERTORY GRID TECHNIQUE

This chapter has been orally presented in part at the International Continence Society in Christchurch, New Zealand, in 2006 entitled 'Development of a treatment planning tool for urinary incontinence. Use of the repertory grid technique'[3].

7.1 Personality theories

7.2 Personal construct psychology

7.3 Repertory Grid Technique

7.1 Personality Theories

Personality is well known to have an impact on disease. For example type A personality (impatient, hostile and aggressive) is strongly related to cardiac disease[129] and type D personality (negative affect, social inhibition and a tendency to be less healthy) is felt to negatively influence selection bias in study populations[130]. There have been many personality theories proposed over time. The ancient Greeks theorised that personalities may, at least in part, be due to a predominance of a particular fluid[131]. The sanguine (blood) type is pleasant, cheerful and optimistic; the choleric (bile) type has a hot temper with a yellowish complexion and tense muscles. The phlegmatic (phlegm) temperament is characterized by slowness and laziness and the melancholic (black bile) temperament is sad, depressed and pessimistic[132].

There are three broad categories of personality theories – psychoanalytic, behaviouristic and humanistic[133].

- Psychoanalytic theorists, including Freudians, believe that the answers to the important questions lie hidden in the unconscious
- Behaviouristic theories are based on the belief that the answers lie in the observation of behaviour and environment and their relations. Behaviourists prefer quantitative and experimental methods and include Eysenck, Skinner, and Bandura
- The Humanistic approach is often based on a reaction to psychoanalytic and behaviouristic theories. The common belief is that the answers are to be found in consciousness or experience[133]

Personality can be measured using validated universal personality inventories such as the Eysenck Personality Inventory (EPI), the Frieberg Personality Inventory, the Karolinska Scales of Personality (KSP) and the Minnesota Multiphasic Personality Inventory (MMPI). Standard personality tests measure set variables that have been identified through formal psychometric development. However, these items are used across cultures and sub-cultures, a range of ages and both genders on the assumption that the items are applicable universally. Their global relevance, therefore, is limited. Critics suggest that personality is an individual construct and it therefore does not make sense to measure it as though it was universal. George Kelly's theory of personal constructs reflects this theoretical perspective of an individual, non-global approach to personality[104;105].

7.2 Personal construct psychology

George Kelly was born in 1905[133] and developed his theory when setting up a rural clinical service. He recognized the psychological problems faced by the farming community during the depression. Initially he used standard Freudian techniques and found it surprising how readily people took to these explanations of their problems. They appeared to place their faith in him, the professional. In 1946 he became the director of the clinical programme for Ohio State University and it was here that his theory matured. He wrote The Psychology of Personal Constructs in 1955[104] recognising the individual variation in people's thought processes and the validity of everyone's experiences. He was opposed to rigid formal tests of personality. There have since been a number of personal construct theorists such as Fay Fransella[105;109] and Don Bannister[105;107;134].

Personal construct theory (PCT) is based around the concept of constructive alternatism, which is that all of our present perceptions are open to question and reconsideration[105]. In a clinical situation, for example, each clinician may interpret the patient's situation in a different way. Each view may be held with conviction and none of the views may match those of the patient. It may be that all these views are the result of alternative constructions of the situation rather than one view being incorrect. Kelly suggested that people create templates to fit over the realities of the world and this is what creates that person's view of the universe. This process is also known as construing. Construing is an ongoing process, which we use to give meaning to our world. We make and test hypotheses to predict future events. This

process is continually revised based on the evidence we collect. We search for repeated themes in our experience of the world and this is our basis for predicting future events [105]. The life events and factors that are construed are called 'elements'. An element is defined as an entity that can be compared. It may be an event, an emotion, a medical treatment or even a type of chocolate bar! We compare elements looking for similarities and differences. These comparisons form constructs, which have two poles, described as 'bipolar'. One pole (the emergent pole) is the way in which two of the elements are similar. The other pole (the implicit pole) is the way in which a third element contrasts.

Not every personal construct is relevant to everything and is only convenient to anticipate certain events. If a particular construct is not applicable to a particular element, then that element is said to be outside the range of convenience of the bipolar construct. The area of the maximum usefulness of a construct is known as its focus of convenience. The relationships between a person's constructs determine their predictions about the world[133]. Experiences serve to either validate or invalidate their views and their future predictions. The way in which a person construes their world may therefore change. Kelly conceived of personality as something that is changing, evolving and highly idiosyncratic. This takes personality outside the realm of measuring everyone against the same scale.

This conceptual and theoretical stance of Kelly differed considerably from conventional thinking such as the 16 recognized personality factors or the commonly known 'big five'. The 16 personality factors are warmth, reasoning, emotional

stability, dominance, liveliness, rule consciousness, social boldness, sensitivity, vigilance, abstractedness, privateness, apprehension, openness to change, self reliance, perfectionism and tension. The 16 personality factor questionnaire is used in various applications from studying addiction[135] to profiling students with excessive internet use[136]. In the 1960s work in the Air Force found five recurring factors, the 'big five', which are openness to experience, conscientiousness, extraversion, agreeableness and neuroticism[137-140].

Kelly did not feel that this reductionist approach of measuring everyone on the same scale was valid since people differ from each other in their construction of events. Differences between how different people behave in different situations can be explained by the fact that they are viewing the situation differently. Sometimes construing can be similar amongst groups of people such as members of a particular cultural group. This can lead to similar behaviours within groups[25;141;142]. If one person can construe another person's construction process then they may be able to understand their behaviour and play a role in their social processes. By understanding the way another person sees things, we can converse and engage in joint enterprises[105]. This can be a useful technique for a clinician to adopt in order to be able to understand their patients better. The repertory grid technique, which emerged from PCT, is one way for a clinician to engage with their subject in this fashion. Examples of the application of the repertory grid technique to medicine are reviewed in Section 7.3. Further theories have developed from Kelly's work. These include theories that if a person construes their own processes of construction then they acquire a more complete awareness of themselves as a person. Similarly, if a

person is able to construe their own construction of social interaction processes they will be able to actually control their ability to influence their interaction with other people. A common construction must be maintained for a group, such as a family, to remain together with each member making choices, within the limitations of their system, to maintain this common construction[105]. It is unclear how and when constructs are derived, whether we derive constructs from our parents, through construing others or if we are born with a set of constructs.

PCT outlines many differing ways in which people form constructs and relate these to their experiences. One example of this is the concept of constriction and dilation[105]. In constriction, the person narrows the field of their construct. Things that do not fit into this narrow construct are not attended to and this can limit their daily routine. Conversely, in dilation the individual sees a wide range of events as related and can sometimes relate everything to a particular problem, resulting in chaos. In women with UI it is possible that they may relate an inability to perform particular activities to their bladder, when there may be other restrictive causes, which if not identified and addressed, could impair their potential satisfaction. This will be explored further this study.

Emotion can result when there appears to be a threat to an individual's core construct system[105]. Each person may also have a core role, which dictates how an individual interacts with others. When an individual is dislodged from their core role then guilt may be experienced, even if their new role does not involve 'bad' behaviour. Guilt has also been explained as arising from the recognition that events lie outside an

individual's range of convenience of their construct system. Further theories of the origins of aggression and hostility also exist based on PCT. Negative emotions may result from unsuccessful construing and positive emotions may result from validation of construing. In addition the following definitions have been suggested[105]:

- Love – an awareness of validation of one's core structure
- Happiness – an awareness of validation of a portion of one's core structure
- Sadness – an awareness of the invalidation of implications of a portion or all of the core structure
- Self-confidence – an awareness of the goodness of fit of the self in one's core role structure
- Surprise – a sudden awareness of a need to construe events
- Anger – an awareness of invalidation of constructs leading to hostility[105]

There is still much unknown surrounding emotion, particularly in relation to different states of consciousness. The term 'the unconscious mind' has become a term for mental processes considered unreportable and it is felt that more research in this area is necessary[143]. Kelly's original ideas surrounding PCT were later developed both by himself and others. The principal advances have been in the clinical, educational and organizational fields and it is expected that elaboration will continue in the future[144]. Health issues have also been studied using PCT techniques, such as the repertory grid, and these are explored in Section 7.3.

7.3 Repertory Grid Technique[104-109;111;113;145]

Theory of the repertory grid technique

Kelly devised the repertory grid technique as part of PCT and it has been used widely in many different areas including psychology, education and market research[104;105;107]. It is a way of establishing in what terms an individual views his or her own personal world. The results can be very informative and data rich and the technique can be modified to suit the needs of the user.

There are many alternative methods available to study individuals and groups of people. Some specific tests identify particular characteristics such as the Crown Crisp Experiential Index (CCEI) measuring neurotic symptomatology[146]. The MMPI and the EPI are used widely to look at aspects of personality such as neuroticism, extraversion and lying. These tests, among others, have been used to identify the prevalence of psychological and psychiatric conditions among populations with urinary problems as demonstrated in Chapters 8. Other instruments used for similar purposes include the Hostility and Direction of Hostility Questionnaire, the Karolinska Scales of Personality, the State Trait Anxiety Inventory (STAXI), the Centre for Epidemiologic studies Depression Scale, the Illness Behaviour Questionnaire, the Freiberg Personality Inventory, the BDI, the Interview Schedule for Social Interaction and the Hysteroid-obsessoid Questionnaire. The Myer-Briggs uses questions to assign personality types and is not uncommonly used in the business world today to analyse peoples roles within a team[147].

Most psychological tests are of a macrocosmic nature[108]. The macrocosm is the entire universe around us with everything in it. These tests compare a particular

person with others by pinpointing him or her on a scale. They do not observe the variation within an individual. The microcosm, on the other hand, is the private universe of one individual. This includes all the things that the individual knows and thinks about. All people are isolated and distinct microcosms, which must be continually undergoing changes. A psychiatrist or psychologist may treat a patient by intentionally bringing about a change in her microcosm.

The repertory grid technique is ideally suited to study microcosms and may be used to measure variation within an individual. It can identify different elements and distinguish them from one another. The repertory grid technique can be adapted to fit a particular individual and does not rely on comparisons with other cases. It can give a therapist or clinician a picture of the subject's view of reality that can be discussed and worked with[133]. With most tests their reliability is considered to be important and assumes that the subject does not vary. The repertory grid technique is interested in the state of mind, which may change considerably. It is, therefore, preferable for the repertory grid technique to have a low reliability.

There are several advantages of grid techniques. What is being measured is not what the subject imagines is being measured. The technique is therefore opaque and prevents the subject from intentionally distorting responses. The subject tends to think that they are being asked to judge the elements when they are actually being measured on the relationship between their judgmental categories. It is flexible and allows qualitative and quantitative exploration of personal areas, which may be difficult to measure by conventional methods. Questionnaires and interviews usually

assume that the interviewer and the interviewee attach the same verbal labels to things, which may not be the case. In grid testing it is the meaning of verbal labels and relationships between them that is being examined. There does not appear to be a relationship between grid scores and intelligence, sex or age. Some people however have difficulty working with some supplied constructs[107]. The technique focuses attention on the patient's view of their world in their own terms rather than on the practice of categorizing them in terms of a standard professional conceptual framework.

Uses of the repertory grid technique

The grid technique is an excellent device for studying the idiosyncrasies of an individual and it may be worth studying a single case when an elaborate course of treatment is under consideration or in progress[108]. It must be used with skill and insight and requires a considerable amount of time and effort. Grids may be more valuable in connection with treatment rather than diagnosis. Combinations of unfavourable conditions may form a vicious circle and successful treatment may break the circle. Grid techniques may be useful at the start of treatment and used to find the points most open to attack. Later grids can be collected, to see the changes in the impact of the conditions on the individual, as treatment progresses.

The flexibility of the repertory grid technique has the advantage of making it potentially useful for many types of research and for the investigation of clinical problems. Grids can be used to help formulate a hypothesis but they are also useful to test hypotheses. The interviewer can predict what the subject will say based on

their hypothesis and then see if this happens when the grid is performed. Disadvantages of the grid are that it is difficult for some people to articulate the constructs; it is time consuming and prevents comparisons between people. The repertory grid technique is most appropriate for this study as it affords the elicitation of psychological constructs that may be relevant to individual UI sufferers but which cannot be readily captured in the clinical consultation and which are not addressed by standard universal personality tests or QoL measures. Repertory grids provide an individual perspective on the situation that may go some way towards identifying why clinically effective interventions are not reflected in psychological well-being.

Method of performing repertory grids

There is no single method for conducting a repertory grid and variability in methodology will reflect the purpose of the activity. During the technique elements are compared. The comparison of elements results in constructs[133]. Any number of elements can be compared in terms of any number of constructs. The results are set out in a numerical matrix known as the repertory grid. An example of a repertory grid is illustrated in Figure 7.1.

Figure 7.1 Blank repertory grid

	Element	Element	Element	Element	Element
Construct					
Construct					
Construct					
Construct					

Construct					
Construct					

Each cell in the grid represents the intersection of an element with a construct. The three stages of performing a repertory grid are to select the elements, choose the terms to compare elements on and then to compare the elements. The interviewer can draw on information already known and concentrate on what he wishes to know. Elements can be varied and can be virtually anything. They can be supplied in specific or general terms and can be people, photographs, emotions, political parties or even chocolate bars! The construct has two poles, the emergent and its contrast (the implicit pole). With the repertory grid technique there is a choice of two methods of administration. In one method the interviewer elicits from the patient the constructs that appear relevant to him. In the second the interviewer provides him with a ready-made set of constructs theoretically relevant to the illness. Both methods can be combined. Constructs elicited from subjects are rated more extremely than those supplied, presumably reflecting the effects of greater personal relevance[106]. Typically three elements are randomly selected and the subject is asked to say how two are the same as each other but different from the third. These descriptions form the constructs. This is repeated for different combinations of elements, allowing the elicitation of further bipolar constructs. On completion, the subject will have produced a set of key constructs that will provide the researcher with information about how the subject sees the topic/issues under investigation.

Repertory grids are a type of sorting test but differ from conventional sorting tests in that there are no sorting materials or sorting categories or any single form of administration or scoring procedure. What is measured is the relationship between sorting categories (constructs) for the subject. After the grid is complete there is a wealth of information and there are different ways of analysing it. All elements must be within the range of convenience of all constructs in any single grid. Otherwise a subject is trying to dimensionalise elements in terms of constructs, which are not applicable. Pilot testing and performing interviews after grids was performed to reduce this error[107] as illustrated in Chapter 10. Subjects in all three research groups had interviews performed after their repertory grids.

Analysis of repertory grids

In this study the constructs underwent thematic analysis by a recognised protocol[94]. Each element and construct was also looked at in turn in the third subject group to examine their expectations and hopes for surgery. There are many different ways that repertory grids can be analysed and represented[110;112;145]. The variation recorded in a grid is entirely microcosmic and the interactions are the focus of interest. Interpretations can be performed by the interviewer who is likely to draw on other information about the case, besides what went into the grid.

Reliability and validity of repertory grids are difficult to define. A test-retest experiment on a large scale cannot be applied to a grid designed for an individual, although it may be possible to apply it to one for general use. When comparing different individuals' grids it may actually be more desirable if they are independent of each

other, since they may reveal more about the informant's attitudes to the elements. Two grids from the same individual at different times are only strictly comparable if they have the same elements and constructs. Changes in the microcosm can therefore be exposed to scrutiny. Tests of validity developed for assessing macrocosmic tests cannot be transferred to individually constructed grids. It is possible for grids for general use as illustrated by Fransella and Bannister[105].

Examples of studies using repertory grids[84;108;109;109;111;113;145]

On reviewing the literature no examples of the use of the repertory grid technique to study any aspect of urogynaecology were found, although it has been used in many other clinical areas particularly psychiatry[148]. Weber used the repertory grid technique to study the hypothesis that patients with cancer would display a restricted body image, focusing on functional aspects of the body[149]. The grid used (the Bodygrid) was specifically designed to explore body image. Six categories of constructs were elicited – emotion, control, activity, strength, function and appearance. The patient expressed the notion that the sick organ or body enters consciousness whereas the absence of dysfunction or pain remains unnoticed. The results confirmed the hypothesis of restriction of body image[149]. The least used constructs related to appearance and this was unexpected. It is felt that the restricted body image view may be a coping mechanism. This study resulted in the recommendation that psychotherapeutic aid, with body-oriented therapy, should be integrated in everyday clinical work.

Ellis used the repertory grid technique to study elderly care by interviewing ten nurses and ten residents[150]. While a sample size of 20 appears small in quantitative research, each interview is data rich and exhaustion of new themes can be reached with such samples in qualitative research. The elements were people, chosen by the participants to fit given descriptions. Constructs were elicited by presenting three elements at a time. Content analysis of the constructs was performed. Three categories were used – personality characteristics, physical caring activities and psychological caring activities. There were differences between nurses' constructs of caring for the elderly and residents' constructs of being cared for. The nurses felt that they could improve themselves as professional carers.

Large evaluated the use of self-hypnosis as a treatment for chronic pain using the repertory grid technique[111]. Five patients were taught self-hypnosis and were evaluated using the Illness Self-Concept Repertory Grid, one and six months after treatment. The subjects initially identified with physical illness but this association decreased with time particularly in those who experienced the most pain relief.

Sheehan used the repertory grid technique to study 12 outpatients with major depressive disorder[148]. The subjects were all undergoing personal construct psychotherapy and their construct systems were monitored using 'multiple perception of the self' grids. Psychiatric and self-rating scales monitored depression levels. Multiple perception of self grids changed more than grids concerning self and others, suggesting that self-concept is important in depression[148].

Rowe assessed 21 patients' preferences for different angina treatments using a modified repertory grid technique[113]. Three sets of options (elements) were used to elicit reasons for preferences (constructs). 'Some treatment' was preferable to 'no treatment'. Surgical treatments were perceived as effective but invasive, frightening and more appropriate for severe symptoms.

In a recent search of the medical literature (on Pubmed) there is very little published using the repertory grid from 2005 but there are several articles in 2010. McEachan used repertory grids and focus groups to explore similarities and differences amongst health-related behaviours[151]. Repertory grid interviews were performed with 25 people along with three focus groups and ways of describing health behaviours were identified. In the second phase, 180 people rated 20 health behaviours on each of the key characteristics. Findings included that physical activity was perceived as effortful, with long-term pay-offs[151].

Vogt performed repertory grid interviews with 18 adult smokers to elicit personal constructs underlying perceptions of effectiveness of a range of medical interventions to stop smoking, prevent heart disease, reduce pain, lose weight and treat depression[152]. The effectiveness of stop-smoking interventions was underestimated relative to interventions to prevent heart disease[152]. In a separate publication Vogt used the repertory grid technique to explore the perceptions of effectiveness of medical interventions amongst GPs[153]. GPs judged the effectiveness of medical interventions using two broad dimensions – the extent to which the intervention required patient effort and the size of the impact of the intervention[153].

Roland captured the burden experienced by spousal caregivers of individuals with Parkinson's disease using the repertory grid technique[154]. It was felt that quality of care and QoL for patients with Parkinson's disease could be improved by improving QoL of caregivers[154]. The successful use of repertory grids in clinical situations, as described, supports the decision to use this technique in this study.

Use of repertory grids to study psychological aspects of urogynaecology

Urogynaecological complaints, including UI, are very personal and it is likely that women have highly individual reactions, thoughts and feelings in relation to their symptoms and how they live with incontinence. The repertory grid technique is ideal to explore these microcosms and has numerous advantages over other methods:

- It allows highly individual data collection on each subject. This was very important in this work as it was important to start with a blank canvas, rather than making presumptions on behalf of the individuals within the selected population
- It does not require a particular level of education or literacy. This meant that more subjects could participate and they would be more likely to represent the entire population
- It does not ask direct questions about UI which people often find embarrassing. While many of the subjects will have presented themselves for treatment and are therefore prepared to talk about UI there may be aspects they would not openly discuss. This opaque methodology allows indirect exploration of such issues if they are important to the subject

- It elicits what people think is important without presumptions by the researcher. Most QoL studies use questionnaires and the responses are limited by predetermined answers that may be selected or scored. A questionnaire will not allow for any new factors to emerge
- There are no limitations on what the subject can include, there are no fixed categories, answers, choices
- It is amenable to various methods of analysis
- It is a recognized research technique
- It is considered to be qualitative but can be quantitative in its analysis
- As a qualitative technique it recognizes that the experience of each individual is important and does not put a weighting on counting the frequency of findings within the population. It allows even one mention of a concern in one subject the platform to be included in the results. This is an advantage in being able to address the entire area of experience, emotion and treatments in this population

The disadvantages of the repertory grid technique for this work are that:

- It can be time consuming. This was not an issue within a research context. It is not suggested that this methodology is used on a day to day basis to assess patients, although it could be useful for the occasional challenging case
- It requires the researcher and subject to speak the same language
- It requires analysis, not giving an instant ‘score’ or result. This was not a problem in the research context, where the results are data rich and can be analysed for each individual and in patient groups

- The results require interpretation
- Combining data from a large number of subjects can lead to large amounts of data, containing wide-ranging findings that can be challenging to handle in analysis. Thematic analysis was the preferred method in this study

Alternative study methods and their reasons for rejecting them as the main research method in this study are:

- QoL questionnaires - These predetermine the possible results and do not allow for anything new to emerge. They rely on quantifying a problem or issue rather than determining how much one thing bothers one person over another thing
- Symptom questionnaires - These gather presence and sometimes severity of symptoms. They may not tell us how much they bother the patient, if at all. They presume that symptoms are the main problems
- Personality questionnaires - These would certainly detect personality traits but nothing else and are too limiting.
- Interviews - These were included in this study to augment the repertory grid technique. It was felt that the interview alone would possibly focus directly on the issues while the repertory grid technique allows indirect study into the area

Women whose UI is ‘cured’ do not necessarily feel psychologically improved. This suggests that standard measures are not tapping into the deep-seated psychological sequelae of UI and therefore a different approach is required. Repertory grids meet these requirements. PCT and repertory grids concern themselves with individuals.

For this reason large sample sizes are unnecessary. While this flies in the face of current evidence based medical research, the gold standard method, the randomised controlled trial (RCT), would not reveal the psychological and experiential information required for this study. The sensitive nature of the UI means that repertory grids are highly suitable here.

CHAPTER 8

LITERATURE REVIEW

This chapter has been presented orally in part at the Ulster Gynae Urology Society in Belfast in 2006 entitled 'Psychological Aspects of Female Urinary Incontinence'[155], at the Midland Urogynae Society in 2005 entitled 'Psychological aspects of urinary incontinence'[7] and in part to the International Continence Society in 2005 entitled 'Is dry happy?'[5]. In addition this chapter has been presented in part by poster presentation at the International Urogynaecology Association (IUGA) meeting in Athens in 2006 entitled 'Is there a place for cognitive behavioural therapy in urogynaecology?'[4].

8.1 Methods

8.2 Women's experiences of urinary incontinence

8.3 Associations between urinary problems and psychological problems

8.4 Psychological interventions

8.1 Methods

The literature review focused on three main areas as outlined in Table 8.1.

Table 8.1 Outline of literature review

Literature review	Topic	Research aim	Section of thesis
1	Women's experiences	To examine the work already done	8.2

	of UI	on women's experiences of UI. To identify themes to include in the future treatment planning tool thus increasing its content validity	
2	Associations between psychological and bladder problems	To explore the associations between psychological and bladder problems. To identify areas not currently being addressed by traditional UI treatment	8.3
3	Psychotherapeutic interventions in UI	To see what psychotherapeutic measures have been studied in UI and their effectiveness. To see if traditional UI treatments have been evaluated in psychotherapeutic terms	8.4

A qualitative thematic review of the literature was performed for each of the three topics. The method of choice for reviewing literature regarding treatments is the systematic review but this is not appropriate in this study. Systematic reviews are reviews of available research on a given area to give a combined outcome on a particular intervention. Decisions are made on which studies to include, what outcome measures are relevant, what quality criteria to adopt and how to conduct and interpret the systematic review. A well established example is the Cochrane collaboration[156] set up in 1993 and covering wide ranging healthcare topics. The

Centre for Reviews and Dissemination (CRD) is part of the National Institute for Health Research and undertakes systematic reviews of health and social care interventions and the delivery and organisation of health care[157], informing decision making in health policy and practice. Systematic reviews are stronger the more rigid the selection criteria and can only focus on small aspects of treatment interventions. This restricts the application of the methodology. Patient perspectives on treatments are rarely a topic looked at in systematic reviews because the data are too subjective and for this reason the systematic review was not used for the first literature search in this study. Similarly the second and third reviews are on topics with little consistency in design, intervention or population and risk being rejected by the systematic review process. An additional aim of the qualitative literature review was to assess the need for further work in this area and to ensure that this work has not already been performed.

A literature search on Cumulative Index to Nursing and Allied Health Literature (CINHL) for qualitative papers on UI resulted in a wide range of papers with differing populations, methodologies, aims and objectives. The search was also updated intermittently using Pubmed. The papers differ so much that they are not amenable to a systematic review and indeed risk being rejected by the systematic review selection process. The papers have been looked at individually as they are enlightening on the area of study even if they cannot be grouped together in a uniform manner. The first literature review, regarding women's experiences of UI, involved reduction into underlying themes and categories by thematic content analysis allowing the emergence of themes and categories in each research paper[158;159].

8.2 Women's experiences of urinary incontinence

The themes from the literature follow. A summary of each of the studies is presented in Appendix VIII. The themes are explored below:

- Barriers to seeking help for UI
- Emotion
- Perception of UI
- Self-image
- Experience of suffering with UI
- Coping and management
- Clinical care
- Issues for carers

- **Barriers to seeking help for urinary incontinence (UI)**

There was a feeling that UI is a condition of older women and this stigma prevented younger women seeking help[27]. UI was seen as a socially unacceptable topic of conversation thereby inhibiting presentation to health professionals[27]. Other barriers to help seeking included embarrassment[25;118], shame[118] and generational differences in attitudes towards disclosing personal matters[118]. Older people accepted UI as an inevitable part of aging that they expect to manage themselves[118]. Language was a barrier to seeking help and obtaining advice, as studied in a group of Pakistani women[25].

- **Emotion**

Emotions included sadness, regret, fear, embarrassment, anxiety, worry, shame and isolation. A sense of sadness and regret for loosing freedom, spontaneity and QoL was expressed[27]. Some people lived in dread in anticipation that the incontinence might get worse[27]. Some women had low self-esteem with expressions of shame[25;118], dirtiness[25], embarrassment[25;118], sinfuness[25] and self-blame[25]. Anxiety was experienced comprising fear, mental stress, worry, fear of not being able to find a toilet quickly and fears for the future[25]. Some women reported feeling depressed[25]. Emotions also related to dependence on others[117] and feelings of isolation[160;161].

- **Perception of the condition of UI**

UI was perceived as a condition of older women to such an extent that this stigma prevented younger women seeking help[27]. It was considered to be a socially unacceptable topic of conversation[27] with a vague and difficult to grasp nature[27] and was seen as unclean. In the Muslim community women are denied prayer if they are incontinent until they can clean themselves and resume prayer[25]. The women felt sinful and had low self exteem[25]. UI can also be seen as a problem of personal control[27].

- **Self-image**

Some people focused on the ways their life had been affected by UI[27]. Sufferers can hate their own bodies and feel it is their own fault that they suffer UI because they did not do PFMT[27]. Low self esteem comprised feelings of shame, dirtiness and

embarrassment[25]. Feelings of loss of self-control resulted in shame, humiliation, fear of ridicule, secrecy, difficulty accepting incontinence and diminished self-concept[25].

- **Experience of suffering with UI**

The beginning of incontinence was rarely clear[27]. There was an inevitability with no clear plan of action[27]. Careful anticipation, mindfulness and modification of lifestyle became a way of life[27] with obsessive bladder emptying[25;27], toilet mapping[25;27], route planning[25;27], selecting safe outings and activities[27], avoiding dangerous movements[27], fluid restricting[25;27] and clothing restrictions[27]. The aim was to reduce the risk of leakage[25]. Another focus was on incontinence management. This comprised practicalities such as washing and changing routines and use of absorbant products[25]. Marital problems occurred as a result of poor bladder control during sex with planned trips to the toilet before and after sex[25]. For Muslim women UI interrupted prayer and there were resulting relationship problems and stress[25]. There was a loss of independence with UI with the loss of physical capabilities[117] and an inability to maintain personal hygiene and independent toileting. Some sufferers were unable to continue with their spousal or parental role[117]. While some found life with UI isolating[27] there was a benefit to sharing problems through talking[25].

- **Coping and management**

The maintenance of normality may involve a great deal of work[27] and careful anticipation and mindfulness become a way of life[27]. The main aim was often to reduce the risk of incontinence episodes[25;27]. This included obsessive bladder emptying, toilet mapping, route planning, selecting safe outings and activities,

avoiding dangerous movements, fluid restricting and clothing restrictions[27]. Managing episodes of incontinence was also important[25]. Some women bought pads and pants in bulk and carried spares[27]. Other practicalities included protecting soft funrishings[27]. Hygiene is a concern and women checked themselves for odour with some choosing to use vaginal deodorant and deodorised pads[27]. Some cleared up immediately and threw away soiled underwear[27]. Other coping strategies included muddling on with it, minimising it and renaming it[27]. Some women paid studied inattention to it[27], therefore claiming to be satisfied with current management. A maintenance of secrecy was part of some people's management strategy[27]. UI was seen as a threat to self-esteem and if self-esteem was maintained then a normal life may have resulted[26]. Prayer helped to relieve stress due to incontinence in a group of Pakistani Muslim women[25]. People found support through humour, hope, personal motivation, prayer, friendship, physical aid from people or institutions and spousal support[117]. Problem sharing with other women was also valued[25].

- **Clinical care**

Patients gave more credit to QoL, interpersonal aspects of care delivery, and organisational aspects of care such as access, availability and convenience[116]. Information was important with some people just wanting information regarding causes of incontinence and self management[116]. Self care systems helped some women to cope[26]. Inhibition, language barriers and perception that health professionals were unresponsive to problems affected communication and comprehension. Satisfaction with treatment of a group of Pakistani women was increased when an interpreter was used and if they were seen by a female clinician,

particularly if an examination was required[25]. Pakistani women have distinct cultural, language and religious characteristics that need to be understood by health professionals[25]. It was suggested that health beliefs influence improvement because self reported wetting measures improved in all groups of a study (comparing control, education and PFMT)[162]. There was a suggestion that nurses should teach about UI treatment and address psychosocial aspects to minimise the impact of UI[117].

- **Issues for care givers**

Issues for care givers included the struggle to balance self, care giving tasks and role expectations[117]. There were financial concerns regarding using hired help[117]. Caregivers suggestions included physical modifications, accepting help, finding time away from care giving[117]. Caregivers felt that nurses should educate patients about UI and address psychosocial aspects to minimise the impact of UI[117].

8.3 Associations between urinary problems and psychological problems

Emotional and physical states are intertwined and links between emotional states and the immune system are already well recognised[163-166]. An example of this is the demonstration of immune alterations in bereavement and depression. Clinical depression is associated with increased numbers of circulating neutrophils and reduced natural killer cell activity and is as a result of the production of cortisol in response to stress. The stressful event of the death of a family member is associated with depression and an increased morbidity and mortality[163]. A meta-analysis of 300 articles showed that stressors lasting minutes were associated with upregulation of parameters of natural immunity and downregulation of some features of specific

immunity[167]. Chronic stressors were associated with suppression of both cellular and humoral measures. Subjective reports of stress generally did not associate with immune change. In some cases, age or disease also increased immune vulnerability[167].

Many of the qualitative studies reviewed in Section 8.2 and Appendix VIII demonstrated worries or concerns of patients and it may be that there is a psychological element to UI and how it is experienced. To investigate this further a literature search of the Cochrane database, Medline and Psychinfo was performed. Selected citations contained within these papers were also included in this review. Search terms used included ‘incontinence’, ‘psychological tests’, ‘personal construct’ and ‘screening’.

The association between the passage of urine and the psyche has long been recognised. In 1941 Menninger pointed out certain erotic and aggressive values in urination[168]. He gave examples of particular individuals who had complaints of urinary frequency and when he had explored them in detail he postulated that they use the frequency as genital contact in place of sexual activity. He believed that this starts as a childhood phenomenon and can carry on or even start later in life. Yazmajian outlined other cases where frequency and urgency relate to suppression of weeping felt to be related to patients’ relationships with their mothers[169]. Psychiatric factors may contribute to the cause of UI[170] and there may be consequences on QoL. Incontinence itself can produce a variety of emotional responses including embarrassment, shame, anger, guilt and denial as illustrated in detail in Section 8.2.

These reactions can lead to women failing to present with their urinary problems. Urge incontinence may have a psychosomatic component. It is difficult to establish whether it is the psychological problems causing the urinary symptoms or the urinary symptoms causing psychological problems or a combination.

Molinski describes how masked depression may be the cause of several different symptoms in obstetrics and gynaecology including genital pain, impairment of sexual functioning, dysfunctional bleeding, urinary disturbances, painful pregnancy, secondary amenorrhoea, backache and the pressing desire for operations[171]. Psychological symptoms may have visceral manifestations and physical symptoms may precipitate anxiety. Most patients will have a physical and a psychological component. Masked depression is described as the situation where the patient has only physical complaints and conscious psychological depression has receded into the background[171]. It is estimated that 10% of patients with gynaecological complaints have masked depression[171]. Masked depression was found in cases of UI without organic findings and in cases of urination during sex, urinary retention and painful urge to urinate. Changes in emotional state have been shown to alter cystometrically with increased intravesical pressure during conversations deemed to be emotionally stressful[172].

Psychological factors are included in QoL measures along with physical and social factors. There are several different QoL measures currently in use, some of which have been designed specifically for evaluation of patients with UI, such as the Kings Health Questionnaire. These may be useful in measuring success of various

therapeutic measures but it can be difficult to know how much change in QoL equates to success or cure[80]. QoL tools are a useful way of collecting QoL issues on a population. They may not, however, address the specific issues and needs of an individual. The tools tend to be questionnaire based and there is consequently no scope to gather additional information not included on the questionnaire that may be of great importance to a particular individual. It is this reductionist approach, which limits QoL tools but they do have the advantage of being easy to administer and collate data.

The strong psychological component to urination is seen in non-clinical cases as demonstrated in the shy bladder syndrome where micturition is altered merely by the presence and proximity of another individual[173-176]. Psychiatric symptoms have been measured in people with bladder complaints in the literature. The majority of these have used validated questionnaire based tools. Rees found a much higher prevalence of psychiatric symptoms in patients suffering from recurrent cystitis. In many of the cases the psychiatric symptoms predate the bladder symptoms[177]. Depression has been shown to be increased in people with DO[125;178;179], sensory urgency[120] and UI[180]. Neuroticism is increased in people with UI[114] and OAB[125;128] and anxiety has been observed in those with recurrent cystitis[177], DO[125] and sensory urgency[120]. Hysteria and hypochondriasis scores are higher in people with urethral syndrome[181] and DO[125;179]. People with urethral syndrome also may have higher schizophrenia scores[181]. Norton found that patients with urinary complaints that were not demonstrable on cystometry tended to have psychiatric scores similar to those of

psychiatric outpatients. These studies are summarised in Table 8.2 and details of the instruments used in each study are tabulated in Appendix IX.

Table 8.2 Summary of studies investigating the link between urinary problems and psychological problems

Author	**Results**
Carson[18] [1;181]	Significant increase in the tendency to exaggerate symptoms, hysteria, hypochondriasis and schizophrenia
Rees[177]	Patients with recurrent cystitis had more free-floating anxiety, obsessionality and somatisation than normals. Same scores as psychiatric controls for hysterical traits. Patients with DO had high scores for free-floating anxiety and somatisation. Patients with inhibited micturition had higher scores for free-floating anxiety. Bladder outlet obstruction had high scores for free-floating anxiety, obsessionality scores higher than psychiatric controls, very high scores for extroversion and neuroticism, low detrusor voiding pressure. Obsessionality and hysterical traits were similar to psychiatric controls. Urge incontinence had higher hysterical traits scores. Depression and hysterical traits increase with age. Young patients with DO had particularly high scores for somatisation.
Stone[178]	All patients had severe life situation problems in the environment and in significant relationships. 15 (out of 18) had partners but were too indisposed by urinary symptoms to participate in sex, 17 patients had chronic depression, 10 patients had functional symptomatology

	(headaches, backache, gastrointestinal symptoms).
Ferrie[128]	The mean neuroticism score was high. Patients with DO had a higher neuroticism score than those with sensory urgency. Introverted patients do better than extroverts with bladder retraining.
Freeman[125]	DO women were higher than published norms for obsessionality, somatic anxiety, depression and hysterical personality traits. Lower paranoid hostility in the DO group than normals. DO women were higher than USI for free floating anxiety, phobic anxiety, neuroticism, hostility and depression.
Morrison[114;120]	Significantly higher than normal neuroticism scores for all patients referred for bladder investigation. No higher in patients with DO than in the group as a whole. Neuroticism score was not related to treatment response.
Macaulay[120]	Significantly more anxious than normal population. Patients with DO or sensory urgency are significantly more anxious than patients with SUI or general medical inpatients. Anxiety scores were similar between patients with SUI and general medical inpatients. Urodynamic patients were more depressed than normals but not as depressed as psychiatric inpatients. Depression scores were higher with DO than SUI. All groups had higher than normal scores for phobic anxiety and functional somatic complaints and hysteria
Norton[127;127]	No significant difference between DO and USI groups. Patients with no detectable abnormality on urodynamics showed high scores within the range for psychiatric outpatients
Walters[1]	No difference between USI and DO groups. Subjects with DO scored

[79]	higher than controls for hyperchondriasis, depression and hysteria. Significantly abnormal MMPI profiles were found in 86% subjects with DO, 69% subjects with USI and 37% of continent controls. DO group had a lower frequency of uplifts and greater intensity of hassles than continent controls. Both incontinent groups had more sexual dysfunction than controls and there were no differences between the 2 incontinent groups. 68% women with USI and 34% with DO said urinary symptoms interfered with sex.
Morrison [126]	47.9% had significant psychiatric morbidity
Lagro-Janssen [182]	No difference between patients with DO and other types of incontinence
Berglund [183]	Incontinent for more than five years had higher somatic anxiety, psychic anxiety, psychasthenia and suspicion than continent controls. USI patients had higher somatic anxiety, psychic anxiety, muscular tension, psychasthenia and suspicion compared to continent controls on KSP. On EPI only lie score was higher than controls. Those who were improved/failure one year after surgery - high degree of neuroticism, low extraversion, high somatic anxiety, psychic anxiety, psychasthenia and suspicion compared to cured women. The improved/failure women had a low level of social integration compared to cured women. Predictors of surgical outcome for SUI are duration of SUI, neuroticism and age.

Drutz[184]	The whole group had higher than normal anxiety levels. There were not differences between urodynamic subgroups
Chiara[185]	Patients with DO show more inner anger and anger trait than SUI or MUI. The conviction of illness was greatest in SUI and MUI. Irritability and general hypochondria were greatest in those with DO.
Bodden-Heidrich[186]	Clinically incontinent patients were more compliant, more moderate, more withdrawn, less critical, more anxious and had higher inner anger than normals. Patients with USI were more anxious and more withdrawn. Patients with DO had greater willingness to direct anger inwards than normals.
Yip[21]	USI or DO had poorer QoL, poorer marital relationship and less sexual satisfaction despite having no change in sexual drive. DO women have higher scores in the emotions domain. USI and DO women had higher severity measure scores than the normal group and lower scores for marital relationship. Also lower sexual satisfaction but same libido.
Heidrich[180]	UI scored significantly lower than those without UI on purpose in life, autonomy, and affect balance. UI had significantly lower self-esteem than without UI. More bother from symptoms including aching, stiffness, tiredness, pain, breathlessness, itch, weakness and concentration/memory problems.
Das[123]	Before treatment there were detectable levels of depression and reduced QoL. Three months after the treatment QoL and depression improved. The delayed treatment group had a worsening of their depression and

	QoL.
Lin[187]	Incontinence impact correlated with symptom distress. Women with high incontinence impact and symptom distress were more likely to seek treatment than those with lower impact and symptom distress.

8.4 Psychological interventions

Section 8.3 explored the link between urinary problems and psychology. This section explores how this information can be developed in terms of identifying psychological disorders and also examining psychotherapeutic options. There are psychological tests that have been used to evaluate urogynaecological interventions and these are summarised, as are psychological interventions in urogynaecology. The detail of the studies is presented in Appendix X.

Psychological tests

There are many tests in use to identify personality types and underlying psychological and psychiatric conditions. A variety of these have been used in women with urogynaecology complaints. Specific QoL scales for urogynaecology complaints include the Kings Health Questionnaire (KHQ)[80], the CUI (coping with urinary incontinence)[188] and the YIPS (York incontinence perceptions scale)[184] and most of these address psychosocial distress at least in part. More general personality and psychological scales include Crown Crisp Experiential Index (CCEI), Eysenck personality index (EPI), Sabbatsberg Depression Self Rating Index (SDSRI) and state trait anger expression inventory (STAXI).

Some studies have looked at established incontinence treatments such as bladder retraining and surgery and have included psychological measures in their outcome measures, while others have used psychological treatments such as hypnotherapy or psychotherapy and used various outcome measures including cystometry and symptom evaluation[20;189]. QoL is now an expected outcome measure in lower urinary tract research and there is a choice of general and disease-specific tools[190].

The questionnaires and tools that are used to identify psychosocial problems are useful to place different individuals on a scale or to compare groups of individuals. They will only provide information on the factors that the particular tool is designed to detect. If the individuals have issues, problems or concerns that are not being tested for by the tools used then they will go undetected and may remain unresolved by treatment. These tools look at outcomes rather than selecting treatments.

Psychological therapies

Psychological therapy was used by Hafner in patients with urge incontinence and it was found that patients with high neuroticism responded best to treatment[10]. A further study by Macaulay using psychotherapy for patients with DO or SUI, randomly allocated patients to therapies and used various measures to evaluate outcome, including mental state visual analogue scales (VAS), CCEI and the Wakefield depression scale[11]. Patients who underwent psychotherapy showed improvements in nocturia, urgency and incontinence. Those who underwent bladder retraining had improvements in mean detrusor pressure rise, first sensation to void, state anxiety,

depression, urgency, nocturia and incontinence. Those who received medication showed improvements in frequency and state anxiety. State anxiety is usually temporary, short-term and reactive while trait anxiety is long term.

Hypnotherapy was evaluated by Freeman as a treatment for 50 patients with DO[20]. After treatment 29 patients were symptom free, 14 felt there was an improvement while seven patients felt that there was no change. On cystometry, 22 patients were stable after treatment, 16 were improved and six did not show any improvement. Cognitive behavioural therapy (CBT) was evaluated by Garley in 10 women with UI[19]. They were evaluated by various measures including the Hospital Anxiety and Depression Scale (HADS). There was no change in anxiety or depression but improved incontinence related QoL and modest improvements in bladder functioning[19]. The problem with the above studies is that they are all quantitative and there is usually randomisation. In this methodology some of the subtleties of treatment may be lost.

Psychological evaluation of traditional UI treatments

Obrink used the EPI and SDSRS to evaluate women with SUI previously having undergone pubococcygeal repair[191]. Patients with symptoms but no signs had high neuroticism and depression scores. Patients with signs but no symptoms had low neuroticism and depression scores. This may explain why some patients complain bitterly of symptoms that cannot always be demonstrated. It may be possible that women who are neurotic or depressed experience their symptoms to be more severe than women who are not neurotic or depressed. Conversely those who are not

neurotic or depressed may be better able to cope with their condition such that they do not report symptoms. This example supports the theory that there is a psychological component in how disease is experienced. It may be possible to use this information to benefit patients by addressing it through individual treatment plans and this thesis will explore this possibility further.

Ferrie used the EPI to evaluate a group of patients undergoing inpatient bladder re-training[128]. On hospital discharge 88% patients were improved. This fell to 57% at three months and 38% at six months. Neuroticism scores between responders and non-responders were not significantly different in patients completing EPI. Patients with DO on cystometry who completed EPI (n=17) did not show a significant difference between responders and non-responders. Introverted patients responded better to bladder retraining. Discussion suggests that introverted patients with low neuroticism scores may respond better to inpatient bladder training[128]. This is one example of a way that a tool (in this case the EPI) could be used to identify patients who are likely to benefit from a particular treatment.

Morrison used the EPI to evaluate patients attending urodynamics before and after various treatments[114]. Overall, 53% patients completing the questionnaire responded positively to therapies while 25% of patients were lost to follow-up. No difference in neuroticism scores was found between the successfully treated group and others. There was no difference in neuroticism scores for pharmacological treatments as opposed to other treatments[114].

Psychological status was measured before and after SUI surgery by Rosenzweig[192]. Patients with successful surgery had improved psychological status while patients with unsuccessful surgery had an increase in depression[192]. It may be difficult to determine if it is the improvement in SUI causing the improved psychological status or the reverse. It may even be a combination of these effects.

Lee used behavioural and educational measures for patients with UI of various types. Evaluation was with various measures including YIPS and self perceptions of symptoms[32]. There was a reduced incidence of incontinence in the treatment group with 16% being cured and 41.5% improved. The YIPS indicated that the treated group were better able to cope with their incontinence than the controls[32].

Psychological measures were used by Berglund for women awaiting SUI surgery[115]. Controls were women having routine gynaecological checkups. Patients with failed surgery had more neuroticism, less extroversion, higher somatic anxiety, psychic anxiety, psychasthenia and suspicion and lower levels of social integration. Duration of SUI and degree of neuroticism predicted outcome to surgical treatment in 80%. Women objectively cured had a decrease in neuroticism one year after surgical treatment. Women objectively cured had lower BDI scores before and after surgery. Women with failed surgery had lower availability of social integration and adequacy[115].

Das measured health related QoL and depression using the BDI for people before and after sacral nerve stimulation therapy for people with voiding dysfunction[123].

Baseline depression and QoL were worse than the general population but improved three months after treatment commenced. Those in whom treatment was delayed showed a deterioration in QoL and depression scores[123].

Burgio observed psychological improvements in all treatment arms of a study of women over 55 years of age with persistent urge incontinence[67]. The psychological instrument used was the Hopkins symptom checklist. Behavioural treatments appeared to be the most beneficial in reducing distress and interestingly the reduction of distress did not always correlate with a reduction in incontinence[67]. Kelleher used the short form-36 and the KHQ to measure QoL before and after treatment with extended release tolterodine for OAB[122]. Benefits with treatment were demonstrated[122].

Lamb examined group versus individual physiotherapy for women with SUI and/or urge incontinence in terms of cost, symptom severity and QoL[44]. While initial patient preferences were weighted towards individual treatment the outcomes did not show a significant difference between group and individual treatment. The authors recommend group treatment as it is less expensive than individual treatment[44]. Non-attendance was not a problem for the group treatment in this study but whether this motivation holds outside the research setting remains to be seen.

Biofeedback was studied by Tadic in terms of psychological burden[45]. It was found to improve psychological burden and this effect was twice as great in those with a history of depression. This effect was related to changes in perception of control. The

authors feel that because psychosocial factors were not previously examined that the benefits of biofeedback may have been previously underestimated by focusing on incontinence outcomes alone[45].

8.5 Summary

There is some literature on women's experience of UI. The methodologies and the patient selections differ. Nonetheless, it has been possible to extract themes on this topic, which can be used in the development of a treatment-planning tool. The association between psychological and bladder problems has been studied. There are many tools used and variations in subjects, conditions and outcome measures with associations shown in most studies. Psychological interventions have been occasionally studied in UI but these studies are rare. The measure of traditional UI therapies in psychosocial terms has revealed that there is more to outcome that leakage. There are no studies working towards the development of an individualised treatment-planning tool, making this study unique.

CHAPTER 9

FOCUS GROUP

9.1 Focus group methodology

Focus groups are a form of group interview generating data by focusing on communications between participants and the researcher[102]. The participants are encouraged to talk to one another adding another dimension not found in one-to-one interviews where the interaction is between the researcher and a subject. It is a particularly useful method to explore people's knowledge and experiences. Focus groups were originally used by the media to explore people's reactions to films and television programs. They now have much wider uses such as assessing health education messages, understanding of illness and experience of disease and health services. When group dynamics work well the research can go in unexpected directions. The advantages of focus groups are:

1. They do not discriminate against people who cannot read or write
2. They encourage participation from those who are reluctant to be interviewed on their own
3. They can encourage participation from people who feel they have nothing to say

Disadvantages of focus groups are that:

1. The articulation of group norms may silence those with alternative views
2. Confidentiality is compromised in a group setting

The main aims of focus groups are:

1. To highlight the participants' attitudes, priorities, language and framework of understanding
2. To encourage research participants to generate and explore their own questions and develop their own analyses of common experiences
3. To encourage a variety of communication from participants – tapping into a wide range and form of understanding
4. To help to identify group norms and cultural values
5. To provide insight into the operation of group social processes in the articulation of knowledge
6. To encourage open conversation about embarrassing subjects and to permit the expression of criticism
7. To facilitate the expression of ideas and experiences that might be left underdeveloped in an interview and to illuminate the participants' perspectives through debate within the group

Some participants benefit from talking to people with similar experiences in a focus group[102]. Sampling should be performed so the members are homogeneous to capitalize on people's shared experiences. Sometimes diversity in a group is actually

an advantage so that a wide range of views can be explored. Hierarchy of the participants within a group may inhibit members from lower in the hierarchy disagreeing with their superiors as is often seen in the workplace.

There are various ways of running focus groups. Generally there are about four to eight participants and usually they sit in a circle to facilitate discussion. The researcher often takes a backseat to allow participants to interact with each other. Subjects for discussion can be presented in various ways. A series of statements can be presented on cards for the participants to sort into statements with which they agree and those with which they disagree. It is not the sorting, which is of interest, rather the conversation that is generated by performing the exercise. The conversation can be tape recorded and transcribed or careful notes taken during the focus group[102]. The focus group transcription data is thematically analysed and individual opinions should be distinguishable from group opinions. Attention must be paid to minority opinions and it is not appropriate to quantify the results[102].

Individual one-to-one interviews are more appropriate for tapping into individual biographies, as will be seen in Chapters 10 to 13, but focus groups are better at seeing how knowledge and ideas operate within a cultural context. It is for this reason that the continence focus group results, which were formulated shortly before the original work of this thesis, are being included in this study. The focus group, interviews and literature review should complement each other in the exploration of women's experiences of incontinence and its treatments and add content validity to development of the final treatment-planning tool.

Running the continence focus group

The focus group was run as part of a patient and public involvement initiative in BWH and Philomena Gales, Integrated Care Pathways Developer, compiled the report in November 2004 in response to several documents; The NHS Plan '*A plan for investment, a plan for reform'*[193], The DOH documents '*Good practice in Continence Services' (2000)*[29] and '*Essence of Care'* (2001)[194]. The National Service Framework for Older People (2001) included a specific focus on person-centred care[195] and the local healthcare trust's clinical governance strategy affirms directorates are responsible for delivering integrated care pathways (ICP).

ICPs are tools to improve quality and ensure services are directed around the needs of individual patients[5]. In 2003, as part of the national and local impetus to improve quality of health services and raise standards of care, the urogynaecology services at BWH initiated the development of an ICP for continence services. Staff recognised the need to actively engage with the women who use the services, and in August 2004 the continence ICP development team proposed to set up a patient focus group to increase understanding of patients' experience of continence services. By understanding the issues raised by the focus group, the team aimed to develop the ICP to ensure it is focused around the needs and expectations of the service users.

In August 2004 the urogynaecology clinical nurse specialists from BWH informally discussed the proposed focus group with patients attending outpatient clinics and those who attended the established continence support group to determine whether

the women would be interested in participating in a focus group. A number of patients verbally expressed an interest in the proposed focus group. A member of the clinical governance team outlined a proposed topic guide for the focus group meeting (see Appendix XI). It was designed to promote group discussion of the patient's journey from the onset of symptoms, through diagnosis, treatment, follow up care and discharge. The clinical nurse specialists conveyed written invitations to patients who had previously expressed an interest to participate in the focus group. Twelve invitations were dispatched together with an information leaflet, contact details and a reply paid envelope. Six women responded positively and attended the meeting. One patient was informed of the focus group when she attended clinic on the day of the meeting and joined the focus group. Seven patients who had previously experienced treatment for continence problems participated in the focus group meeting. Two members of staff from the Trust's clinical governance team were also present at the meeting to facilitate the group and to provide administrative and technical support.

The team agreed the optimum numbers of participants would be five to twelve people. Written consent was obtained from all participants to record the focus group and the meeting was audio taped in order to support verbatim transcription at a later date. The meeting was held in a comfortable and relatively quiet environment within the Trust and refreshments were provided. There was a single focus group of seven women conducted. No biodetails were recorded.

At the outset of the meeting the facilitator welcomed and thanked all participants for their attendance. She provided a brief introduction and explanation of the purpose

and anticipated structure of the meeting and offered an assurance of anonymity and emphasized the need for an unequivocal agreement by the group to protect and respect the confidence of all participants. In order to support and promote an environment where participants could unreservedly voice their opinion of clinical care, clinical staff members were excluded from the meeting. The clinical nurse specialists, however, agreed to remain close at hand to provide support for patients if required. The focus group took place on 8th September 2004 and the transcription notes from the focus group meeting were reviewed by the facilitator and emerging themes noted. The results present the views and opinions of participants and were anonymised to preserve confidentiality.

9.2 Focus group results

Details of the focus group are in Appendix XI. Here follows a summary of the main areas of discussion.

- **Start of the problem and seeking help**

The cause of UI was thought to be childbirth, surgery or part of the ageing process. Reasons for delay in seeking help included:

1. A reluctance to accept it was happening to them
2. An unwillingness to discuss an *'embarrassing and personal'* problem – particularly with a male GP
3. Feelings of shame and guilt, lack of knowledge about where and how to seek help
4. An assumption that nothing could be done to treat incontinence

5. An assumption that incontinence was something to be tolerated in old age
6. A misconception of the benefits of pelvic floor exercises
7. Denial with a refusal to believe in the presence of UI and thinking it may be a psychological problem

There were various reasons given for delay in seeking help. Some felt the UI was their own fault. There was a reluctance to tell a male GP but it was difficult to get an appointment with the female GP. Help seeking was prompted after talking to another patient. One person rang a helpline. Another saw an advert by a drug company looking for volunteers for incontinence research. Once seen, one participant felt the GP had very little knowledge and referred her to the practice nurse.

- **Awareness**

It was felt there was not much information but that there was an increasing awareness. Most publicity was from pad manufacturers. An incontinence article prompted discussion with a spouse and then an appointment with the GP. People had been unaware there were specialist continence services in their area.

- **At the hospital**

The importance of the language used to explain symptoms and procedures was highlighted. Examinations and investigations can be humiliating and degrading but information can put people at their ease. Inpatient stays were seen as marvellous, providing discipline and time for information to sink in.

- **Terminology**

The women liked the down to earth terminology – like ‘wee’

- **Treatment**

As part of their treatment women wanted easy to understand information and liked when questions were encouraged. One week as an inpatient allows education, which was helpful. They liked the freedom they had to come and go. Some had problems following surgery. Not everyone understood what would happen at physiotherapy. Some thought it would be group exercises in a gym requiring special clothes. Some were not aware of treatments for incontinence and felt in particular that there was nothing for older people. One woman uses an alarm clock to manage bladder problems at night without medication and her achievement made her feel ten years younger. There was a fear of telling nurses of a setback in case there were no more treatment options resulting in discharge from care. Other members felt the staff would not give up with you, like in other hospitals; they will try something different or change the dose. Some members recommended bringing paper to write down instructions given at the appointment.

- **Environment**

Participants felt tests should be carried out in the hospital environment. They appreciate having a specialised women’s hospital with the environment discretely labelled alongside other women’s services.

- **Information**

Information was accessed through the manufacturers of continence products and national helplines. It was felt there was very little information at the GPs. Participants felt it was likely due to under funding and therefore the commercial sector was responsible for most of the information. They acknowledged that incontinence could lead to other issues (depression, breakdown of family relationships) that had cost implications for medication or psychiatric services.

In the event of unlimited funds the group wished for more information and increased awareness whenever and wherever possible, especially GP surgeries. One person said she would be embarrassed to pick up a leaflet even in the GPs but would consider it if it was in the consulting room. Other suggested areas in clinics, libraries and supermarkets. One person felt the local pharmacist was very helpful regarding pads. It was felt Information should include local contact details.

- **Coping mechanisms**

Some women did not expect a complete cure but aimed to be able to manage comfortably.

- **Continence products**

Participants were initially unaware of continence products, managing with multiple sanitary products and feeling self-conscious, as they were too bulky.

- **Living with incontinence**

UI had effects on self-image, confidence, social life and other family members. Often there is an initial reluctance to accept they were incontinent with an unwillingness to discuss it, feeling distressed and embarrassed by their symptoms.

- **Personal hygiene**

Some people were aware of other people smelling of urine and worry that they too have a smell.

- **Relationships**

UI affects relationships with partners and other family members. Relationships sometimes changed when they had more information and accepted their diagnosis. Treatment helped one woman's marriage. There was a description of feeling shamed and embarrassed and sleeping in separate beds because of worry about leakage and odour. Coming to hospital helped one woman to discuss UI with her husband.

- **Follow-up**

Continuity of care is felt to be important and the relationship with staff is valued.

- **Patient support group**

It was felt that attending the patient support group had positive benefits. Participants did not feel that problems have to be endured in isolation. Talking in the group helped people to discuss the problems outside the group e.g. with their husbands. Some felt it should be available in other areas and at other times so that more people could

attend. The educational element was also valued as there were often guest speakers.

- **Discharge**

Some saw discharge as proof they were better and a cause for celebration. Others felt the review appointment is a crutch they can lean on and wish to keep coming back. Some were worried about what to do if they were discharged and their problems returned and how long they may have to wait if re-referred to hospital. Some felt the nurses inspired them with confidence to manage things themselves but they could be contacted if necessary. Some felt better knowing they could contact staff directly if they had any problems. One woman was reluctant to contact them in case she would be disturbing a busy clinic.

9.3 Conclusions

The themes from this focus group were added to the themes from the literature review and patient interviews to provide content validity for the treatment-planning tool. Information from the focus group was also used to identify areas of unmet need in current management of UI.

CHAPTER 10

PILOT STUDY

10.1 Introduction

The purpose of the pilot trial was to develop a workable protocol. This took the form of action research as is described in detail in Section 10.2. The subjects were selected as users of BWH continence services. They gave written consent to take part in the study and their results are included in the first patient group of the main study. In other words these six women were the first six of the group of 20 women, called Group 1, who were the general group. Both the repertory grid methodology and the qualitative interview technique were refined through this action research. There was a period of reflection after each assessment and then a plan made for the subsequent subject resulting in a robust research protocol, proven to be useable in this population and able to capture information effectively.

10.2 Description

The following account details this process through the action research of pilot subjects. The repertory grid process is described first followed by the process for developing the qualitative interviews. Subjects one to six are the same subjects for the repertory grid and the qualitative interview.

Repertory grid technique

- Subject 1

A blank repertory grid for six elements and six bipolar constructs was devised. The subject was identified through the urogynaecology multidisciplinary meeting. She was felt to present a management challenge and had undergone several previous continence procedures. The repertory grid was devised to obtain six elements and six bipolar constructs. The initial question to obtain the elements from the subject was 'Please name three situations or places in which you find your problems bothersome and three situations or places in which your problems do not matter as much'. To form the bipolar constructs, three elements at a time were chosen, following standard protocol[196]. The grid was randomly pre-marked to indicate combinations of elements to be presented. The subject was asked in what way two were similar and the third different. Due to repeatedly similar constructs emerging, an alternative instruction was given for the fourth, fifth and sixth constructs. She was asked how she felt about two of the elements and how she felt about the third.

The elements she chose were shopping, holidays, socialising, at home, visiting daughters and in hospital. She construed the following bipolar constructs:

At home – Out of the house

People aware of the problem – People not aware of the problem

Familiar environment – Unfamiliar environment

Comfortable – Uncomfortable

Unhygienic – Hygienic

Self-conscious – Not self-conscious

The repertory grid revealed some situations where her bladder is more affected and some situations where her bladder is less affected. This technique meant that by comparing and contrasting elements the following information was gleaned without direct questioning. She finds her problem less bothersome when she is at home, in a familiar environment with people who are aware of her problem. In these situations she feels comfortable and not self-conscious and feels it is more hygienic. In contrast, she is more bothered when she is out of the house or in an unfamiliar environment with people who are not aware of the problem. She feels uncomfortable and self-conscious in these places and feels it is more unhygienic.

The repertory grid was informative but during the process of its completion the same construct was repeatedly formed. She unfortunately required some prompting which is contrary to the whole ethos of personal construct theory. The inability to differentiate verbally between situations is an established difficulty with the repertory grid procedure. These reflections were useful to determine how best to interview the next subject.

- Subject 2

This subject was identified during the course of a urogynaecology clinic as having had multiple unsatisfactory treatments. The same method was used for the repertory grid but it was not possible to get her to come up with situations where her bladder was not a problem. Consequently the grid was performed with only five elements:

If a toilet is occupied

If there is running water

Travelling

At home

Alone

This subject also had difficulty forming constructs and required more help than seemed appropriate to obtain her own true feelings and expressions. This may be partially because of the way the question was asked or perhaps because English was not her first language. Her bipolar constructs were:

Delay – No delay

In control – Not in control

Not having to wait – Having to wait

Feels safe – Does not feel safe

Worried - Relaxed

- Subject 3

This woman was identified as a patient who had many operations for incontinence and was still having ongoing problems and attending the continence service. Her time was limited as she only had 15 minutes to spare. A different approach was used for the third repertory grid to try to make questions less continence-based. In theory, if incontinence really is an important factor in the subject's life then it would be likely to emerge without specific enquiry. The new approach was to ask the participant for things which she liked doing and things she hated doing. In this grid an attempt was

made to score every element on each bipolar construct scale. The reason for this is to give more information and possibly to allow statistical analysis. Interestingly, this subject did not bring incontinence into any of her elements or personal constructs. To illustrate how a completed repertory grid is represented her repertory grid is illustrated below:

Figure 10.1 Completed repertory grid

Elements→ Bipolar constructs	Reading	Watching soaps on television	Bingo with her husband	Shopping	Getting up early in the morning	Drying her hair
Happy(1) – Miserable(10)	2	1	10	9	3	6
Relaxed(1) – Tense(10)	1	2	9	8	6	5
Do it for me(1) – Do it to keep the peace(10)	2	1	8	4	6	5
Peaceful(1) – Tense(10)	2	2	9	10	6	5
Necessity(1) – Not Necessary(10)	1	2	9	7	1	2
Livelihood(1) –	10	10	9	2	1	8

Leisure(10)						

- Subject 4

The fourth participant had a grid constructed in a similar fashion to subject 3. She was asked for things she really loved to do and things she hated to do. She could not think of things she hated to do so was then asked for things she avoided or did not like. She was asked to compare elements in relation to how they made her feel. She was asked to score each element on a scale for each construct. She repeatedly got confused about which end of the scale was which. Her elements were:

Travelling

Gardening

Living alone

Rude people

Loud music

Company

Her bipolar constructs were:

Good – Miserable

Elated – Exacerbated

Wanted – Useless

Not lonely – Lonely

Upsetting – Happy

Relaxed – Disturbing

- Subject 5

Another approach for grid construction was used for the fifth participant. Most of the elements were supplied as follows:

1. Me, before the problems
2. Me, now
3. How I would like to be after treatment
4. How I expect to be after treatment
5. Me, when my problems are/were at their worst
6. For the sixth element she was asked what she enjoys doing the most. She chose gardening.

She was presented with three elements at a time and asked to make comparisons to formulate the bipolar constructs, which were:

Felt good – Felt despondent

Feels that treatment will never finish – Thought that treatment would be quicker

Takes me out of myself – Dwells on problems

Negative – Positive

For two of the combinations of elements she was not able to form a construct. This grid was very successful in stimulating personal descriptions and emotional responses. The participant was tearful at various times and really opened up about how she was feeling. She actually admitted that she was not aware of how upset she was until now when she was talking about it. She had difficulty with two of the six constructs so the grid was incomplete. Nonetheless, it was useful - probably the most

useful grid formulation to that point, and consequently, this format was used for subsequent repertory grids in the study.

- Subject 6

The repertory grid was performed in the same manner as for subject 5. She chose travelling as her sixth element. Her bipolar constructs were:

Happy with body – Not happy with body

Normal – Not normal

Feels hopeful now and thinks this is how she will be – Something to look forward to

Good – Bad

No toilet constraints – May be some toilet constraints

She was unable to formulate a sixth bipolar construct. This was the format devised for the remainder of the first patient group of general patients with UI (see Figure 10.2).

Figure 10.2 Blank repertory grid for study group 1

Elements→ Bipolar constructs	Me before the problems started	Me now	Me – how I would like to be after treatment	How I expect I will be after treatment	Me – when my problems are/were at their worst	*Element chosen by subject. Something they really love doing/ their favourite*

						thing
Bipolar construct formed by comparing and contrasting elements marked / and X	/	X		/		
			/	/	X	
		/		X		/
			X		/	/
	X		/	/		
	/		/			X

Qualitative interviews

- Subject 1

An interview outline was formulated for this initial interview as follows:

- Main current medical complaint
- Other current medical complaints
- Description of current complaints
- Treatment so far
- Previous/other medical complaints

- How do you feel about the problem that you have?
- How do you feel that you cope with your problem on a day-to-day basis?
- How do you feel about the treatment(s) you have had so far?
- What is the thing that had helped you most?
- What was the worst thing about your treatment?
- What is the plan now for your problem?
- What do you expect treatment to achieve?
- How do you think you will be in a year's time?
- How do you think you will be in five years time?

These questions were devised in an attempt to gain a complete picture of the subject's experience of UI and their experiences and opinions of their treatment to date. It also aimed to explore how they feel about future treatments and their future in general. The literature review and focus groups helped to inform this structure. The information gained was useful but there were limitations. For example the interview questions did not capture much emotional flavour and were perhaps too direct and closed. The subject required some prompting, which was undesirable.

- Subject 2

In the second subject's interview a more open style of questioning was used to see what sort of information was captured. She was asked what her main problem was and how this affects her. Then she was asked about previous treatments and other medical problems. The more open questioning allowed her to emphasise what her problems were.

- Subject 3

This subject did not have time for a qualitative interview.

- Subject 4

This subject had a brief interview about her UI and her treatments. She also talked about her hopes for the future.

- Subject 5

The fifth participant had a very meaningful interview. Relatively open-ended questions were used including:

- What are your main problems?
- How long have you had problems for?
- What treatments have you had?

Points and details were clarified with her throughout the course of the interview. She included how she felt about many things including her treatment and interactions with clinical staff and how they made her feel. She felt that, despite getting emotional and crying, the interview had been useful to her, enabling her to get things off her chest. She appeared to be looking for sympathy and reassurance throughout the course of the interview. This was challenging because as a clinician it was tempting to interact and provide reassurances but as a researcher it was the observation that was important without influencing her thoughts and feelings. As the interviews progressed the aim became to ask as little as possible and to allow the subject to talk as freely as possible. This was a much longer interview than any of the previous interviews.

- Subject 6

The interview started by asking what the biggest problem was and about treatments in the past. She also gave very detailed descriptions of her condition and how she feels about it. She also describes her interactions with health care staff. She mentions many other factors such as her marriage and her childhood and the impact these have had on her mood. She also appeared to want more interaction during the interview such as looking for sympathy or reassurances. This was challenging to resist and remain an impartial observer. A certain amount of interaction is required to keep the interview flowing but it was kept to a minimum. The main aim of subsequent qualitative interviews remained for the interviewer to say as little as possible to keep the subject talking for as long as possible.

10.3 Conclusions

This action research phase was crucial for development of both the repertory grid technique and qualitative interviews. The blank grid relating to self at different time periods was formulated as was the grid related to liked and disliked activities. For the qualitative interviews the technique of using open questioning and minimal prompting to obtain as much text as possible, led by the subject, was refined.

CHAPTER 11

MAIN STUDY

GROUP 1

11.1 Introduction

11.2 Repertory Grids

11.3 Qualitative interviews

11.1 Introduction

Group 1 comprised 20 women with general UI problems who were attending the continence services of BWH. The majority were outpatients but some were having inpatient bladder retraining. Their personalised experiences were the focus of this phase and therefore demographic details were not collected. The pilot group of six women (Chapter 10) were included in this group.

11.2 Repertory grids

- **Subjects**

As outlined in Section 11.1.

- **Design**

The repertory grid technique is a recognised method as discussed in Chapter 7. It is not a fixed method and can be adapted to suit the circumstances as required. The

design of the repertory grid for this phase of the study was developed through the first six subjects and this action research is discussed in detail in Chapter 10.

- **Procedure**

Following written consent a repertory grid was performed with each subject. For the first six women this took the format as described in Chapter 10. The remainder of the sample used the grid shown in Figure 10.2. The grid constructs underwent thematic analysis individually and also were combined for a combined thematic analysis using the method described by Attride-Sterling[94]. Each bipolar construct was written onto a record card and then the pile of cards was shuffled. The cards were read in turn and placed in piles with similar constructs. Each pile was checked in turn and reorganised if necessary. Related piles were grouped together on a tabletop. This resulted in a thematic network as outlined in Table 11.1.

Table 11.1 Thematic network process

Order of theme	Physical sorting item
Basic theme	The theme on a record card
Organising theme	The theme related to each pile of record cards
Global theme	The overarching theme for a group of piles
Thematic network	Combined global themes

- **Results**

The thematic network for each subject is illustrated in Table 11.2. The combined thematic analysis for all the constructs from Group 1 is illustrated in Table 11.3.

Table 11.2 Thematic networks of individual repertory grids (Group 1)

1st repertory grid

Global theme	Organising Theme	Basic theme
Environmental	Difficulty	Going out
	Easier	Familiar environment
		With people already aware of problem
Self awareness	Self-consciousness	
	Hygiene	

2nd repertory grid

Global theme	Organising theme	Basic theme
Control issues	Toilet availability	Not having to wait
		Delay
		Toilet is occupied
		Travelling
		At home
		Alone
Emotions	Feeling in control	
	Feeling safe	
	Worried	
Exacerbations	Running water	

3rd repertory grid

Global themes	Organising themes	Basic themes
Enjoys activities	Good feelings	Happy
		Relaxed
		Peaceful
	Reason for doing	Does for herself
		Necessity
		For leisure
Does not enjoy activities	Negative feelings	Miserable
		Tense
	Reason for doing	Does it to 'keep the peace'
		Not necessary

4th repertory grid

Things she likes	Travelling, gardening, company	Good
		Elating
		Wanted
		Happy
		Relaxed
Dislikes	Living alone, rude people, loud music	Miserable
		Exasperating
		Useless
		Lonely
		Disturbing

5th repertory grid

Global Theme	Organising theme	Basic theme
Emotion	Negative	Despondent
		Dwells on problems
		Feeling negative
Bladder	Negative	Thought treatment would be quicker

6th repertory grid

Concerns	Body	Happy/unhappy
	Normality	
	Good/bad	
	Toilet constraints	
Optimistic	Looking forward to the future	Feeling hopeful

7th repertory grid

Emotion	Self-confidence	
	Conscious of problems	
	Hope	For the future
Symptoms	Wet	
Restricted activities	Rules her life	
Normality	Normal	

8th repertory grid

Emotion	Confidence	
	Depression	
	Isolation	
Activities	Restricted freedom	Able to do what I want

9th repertory grid

Concern	Smell	
Restricted activities	Reluctant to go out	Lack of confidence

10th repertory grid

Restrictions	Dependency on other people	Need a lift, not able to use public transport
		Dependent on other people/ lack of freedom
	Going out	Not able to go out
	Other health problems	
Bladder symptoms	Frequency	
General	Bad	

11th repertory grid

Emotion	Negative	Not confident
		Feeling bad
		Degraded
		Low self esteem
Restriction	Activities	Not able to get out and about
		Important to be able to wear trousers

12th repertory grid

Restricted activities	Housework	Washing, vacuuming, ironing, mop floor,
	Motivation	Does not feel like doing things

13th repertory grid

Leakage	Having to hold myself not to leak	
Life	Life is worse/better	
	Not as good as I used to be	
	Other medical problems	
Future	Unknown treatment outcome	

14th repertory grid

Restrictions	Physical	Not able to lift children/objects
	Mental	Having to think where toilets are
		Not feeling free
Symptoms	Leakage	Wet knickers
		Incontinence a problem
Not perfect		

15th repertory grid

Emotion	Negative	Anxiety
		Sad
		Fed up
	Positive	Relieved
		Anger
		Relaxed

16th repertory grid

Feelings	Positive	Confident
		Positive
	Feeling old	
	Nervous	
	Physical	Inactive
		Healthy

17th repertory grid

Self-image	Normality	
	Self-confidence	
	Perfect/not perfect	
	Unclean	
Emotion	Embarrassment	
Problems	Problems in general	

18th repertory grid

Control	In control of the bladder	
Expectations	Expect to be continent	
	Prepared to put up with mild temporary incontinence	
Freedom/control	In control of the bladder	
	Restricted freedom	

	Life is complicated	

19th repertory grid

Bladder symptoms	Leakage	Wet pants
	Urgency	
Restricted activities	Carrying shopping	Needs taxis
Feelings	Negative	Feeling down
		Tired
Other symptoms	Dragging pain	

20th repertory grid

Problems with sex		
Fine		

Table 11.3 Combined thematic network for repertory grids (Group 1)

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Environmental	Difficulty	Going out
	Easier	Familiar environment
		With people already aware of problem
Self awareness	Self-consciousness	
	Hygiene	
Control issues/freedom	Toilet availability	Not having to wait
		Delay
		Toilet is occupied
		Travelling
		At home
		Alone
	Control	In control of the bladder
	Freedom/control	In control of the bladder
		Restricted freedom
		Life is complicated
Emotions	Feeling in control	
	Feeling safe	
	Worried	
	Negative	Despondent
		Dwells on problems
		Feeling negative
		Not confident
		Feeling bad

		Degraded
		Low self esteem
		Anxiety
		Sad
		Fed up
		Feeling down
		Tired
	Depression	
	Isolation	
	Self-confidence	
	Conscious of problems	
	Hope	For the future
	Confidence	
	Positive	Relieved
		Anger
		Relaxed
		Confident
		Positive
	Feeling old	
	Nervous	
	Physical	Inactive
		Healthy
	Embarrassment	
Fine		

Exacerbations	Running water

Enjoys activities	Good feelings	Happy
		Relaxed
		Peaceful
	Reason for doing	Does for herself
		Necessity
		For leisure
	Travelling, gardening, company	Good
		Elating
		Wanted
		Happy
		Relaxed

Does not enjoy activities	Negative feelings	Miserable
		Tense
	Reason for doing	Does it to ‘keep the peace’
		Not necessary
Dislikes	Living alone, rude people, loud music	Miserable

		Exasperating
		Useless
		Lonely
		Disturbing

Bladder symptoms	Negative	Thought treatment would be quicker
	Wet	
	Frequency	
	Having to hold myself not to leak	
	Leakage	Wet knickers
		Incontinence a problem
		Wet pants
	Urgency	
Other symptoms	Dragging pain	

Concerns	Body	Happy/unhappy
	Normality	
	Good/bad	
	Toilet constraints	
	Smell	

Optimistic	Looking forward to the future	Feeling hopeful

Restricted activities	Rules her life	
	Restricted freedom	Able to do what I want
	Reluctant to go out	Lack of confidence
	Dependency on other people	Need a lift, not able to use public transport
		Dependent on other people/ lack of freedom
	Going out	Not able to go out
	Other health problems	
	Activities	Not able to get out and about
		Important to be able to wear trousers
	Housework	Washing, vacuuming, ironing, mop floor,
	Motivation	Does not feel like doing things
	Physical	Not able to lift children/objects
	Mental	Having to think where toilets are

		Not feeling free
	Carrying shopping	Needs taxis

Self-image	Normality	Normal
	Not perfect	
	Self-image	Normality
		Self-confidence
		Perfect/not perfect
		Unclean

Life	General	Bad
	Life	Life is worse/better
		Not as good as I used to be
		Other medical problems

Future	Unknown treatment outcome

Problems	Problems in general

Expectations	Expect to be continent
	Prepared to put up with mild temporary incontinence

Problems with sex	In general

- **Conclusions**

There are wide ranging issues surrounding women's experience of UI. There is a lot more to their concerns than whether they are wet or dry. This is the first group of women in this study to undergo repertory grids and thematic analysis of the constructs. These techniques have proven themselves to be suitable research tools for this work. Many themes have been derived, which can be used for future development of a treatment-planning tool.

11.3 Qualitative interviews

- **Subjects**

The subjects were the same women as described in Section 11.1.

- **Design**

The technique of performing qualitative interviews was refined through the action research undertaken in the pilot study, described in detail in Chapter 10.

- **Procedure**

Subjects had their interview performed after their repertory grid. They had written consent for their participation and were aware that they could terminate the interview at anytime of their choosing. The interviews were not time limited and were free flowing. The subjects were allowed to lead the interview and wander off the topic as they wished. The interviewer asked a minimum of open questions to keep the interview going. The interview was recorded verbatim by hand. It was typed up shortly after the interview was complete. The text from the interview was handwritten onto record cards to facilitate thematic analysis in the same way as that described in Section 11.2 and Table 11.1 for the constructs from the repertory grids[94]. For some of the text statements there may be two themes in which case a further card would be produced so that the statement could be included in all relevant themes. Each interview underwent individual thematic analysis and the whole group was analysed together into a thematic network by a recognised protocol[94].

- **Results**

The results are represented as thematic networks for individual subjects (Table 11.4) and for the whole group (Table 11.5).

Table 11.4 Thematic networks of individual qualitative interviews (Group 1)

1st interview

Global theme	Organising Theme	Basic theme
Treatment	Negative comments	Multiple operations and none have helped
		Physiotherapy was a waste of time
		Annoyed having to pay for catheters (for ISC)
		Not expecting anything of treatment or the future
	Positive comments	Fluid advice was the most useful thing
		Prefers self catheterisation to leaking
Impact of bladder	Areas affected by bladder	Quality of life
		Hobbies
		Holidays
		Toilet mapping
Coping with bladder problems	Coping mechanisms	Copes because she has no choice
		Performs self catheterisation when there is discomfort
		Used to wear pads for incontinence

2nd interview

Global theme	Organising theme	Basic theme
Symptoms	Overactive bladder (OAB)	Frequency
		Sensitive feeling
	Secondary to OAB symptoms	Uncomfortable at night
		Tired the following day
	Symptoms/conditions	Knees, varicose veins,

	unrelated to bladder	diabetes, hypertension, increased cholesterol
Cause of bladder problems	Previous surgery	Repair operation 18yrs ago
Bladder treatments	No help	Trospium
		Physiotherapy
		Inpatient admission
		Previous hysterectomy (she thought it was for the bladder)

3rd interview

INTERVIEW- no interview due to time constraints

4th interview

Global themes	Organising themes	Basic themes
Problems	Bladder	Frequency
		Leakage
	Other	Rheumatoid arthritis
		Circulation problems
		Groin pain
		Swollen ankles
		Abdominal pain
Coping	Ability	Feels she can cope
	Methods	Keeps busy
		Does not dwell on the problem
Emotion	Negative	Gets frustrated leaking after showering and in clean clothes
	Positive	Never gets depressed
Treatment	Operations	Still problems
		Found one op the best treatment she had
		Feels treatment has been wonderful
		Problems passing urine at home with catheter after operation
	Staff	Found staff caring
	Private healthcare	Because of NHS waiting times
		Because problem was distressing
Future	Hopes	Not to have to wear pads

		For improvement in 1 year and 5 years
	Expects	Improvement
		Some problems
	Accepts	Limitations

5th interview

Global Themes	Organising Themes	Basic Themes
Medical problems	OAB symptoms	Frequency
		Urgency
	Bladder Treatment	Tablets had side effects
		Can't remember pelvic floor exercises
		Put through hoops
		Waste of NHS money
	Cause of bladder problems	Emotion
		Loss of height with back problems
	Other medical problems	Back and loss of height
		Eyes
Other people	Staff and health care	Comments e.g. 'without a doubt I'll be seeing you again'
		No continuity of care
		Wanted to see the person in charge
		Detected friction between staff at urodynamics
	Comparison	Family have all been through similar things with their backs and bladders
		Sister said 'get it sorted before you reach my age'
		Stranger (on TV had an operation she was denied, which made her doubt things)
	Secrecy	Does not discuss much
		Doesn't reveal how much it bothers her
		Doesn't want to burden people
Emotion	Self pity/ victim	'I don't think anyone takes me seriously'

		Hopes were dashed when put off the operation as it could make things worse
		Passed on like a parcel/ put through hoops
	Fear	For the future
		Anxiety
	Doubt	
	Feeling dismissed	
	A cause of the bladder problems	

6th interview

Global themes	Organising themes	Basic themes
Medical concerns	Bowels	Has to assist bowels
	Bladder	Leaks with sex
	Bacterial vaginosis	Difficulty accepting diagnosis
Concerns	The future	
	Normality	Wants to be able to do a normal poo
	Sex	Husband left after bacterial vaginosis was diagnosed
		Avoids sexual relationships
		Would loose bladder control during sex
	Odour/hygiene	Important
	Age	Worried about being old
		Accepts that the body changes with age
Healthcare	System	Comments on fund holding, arranging a gynaecology clinic in primary care
	Positive staff qualities	Honesty
		Believes her
		Persistence
		Support
		Communication
		Listening
	Negative staff qualities	Dishonesty
		Concealment
		Not concerned

Emotion	Positive	Relief at being believed
	Negative	Fraught
		Felt abused/victim
		Regret
		Crying
Other people	Concerned for her	Her son
	Comparison	Friend with marital problems
		Patient from same surgeon
		Elderly- fear for future
	Support	Friend - through marital problems
		Staff support
Cause of medical problems	Bladder	Forceps delivery – internal damage
	Tummy swelling	Suprapubic catheter
	Bowels	Previous surgery

7th interview

Global themes	Organising themes	Basic themes
Other medical problems	Heavy period	
	Diabetes	
Bladder symptoms	Wet with activity	
	Has to change pads	
Cause of bladder problems	Difficult childbirth	
	Hysterectomy	
Restricted activities	Going out	
	Keep fit	
	Shopping	
Trigger for presentation	Fed up	
Negative staff impression	Secrecy	Not told why things went wrong
		Felt left in the dark
	Felt criticised	
	Unapproachable	
	Felt told off	Like a naughty child
	Disappointed	Told things were not available because of diabetes
Other people	Husband	Problems with sex- usually understanding
		Sometimes says he 'wants to make love to his wife'

		Tried to reassure her about smell - but can't
	Secrecy	Has not talked to friends and family
	Not understanding	People can't understand until they have the problem
Emotion	Regret	Of having hysterectomy
	Fed up	Being wet
	Devastated	Because of reduced treatment options
	Self-conscious	
	Hate	Hates being wet
		Hates wearing incontinence pads
	Lacks confidence	
	Hope	Hopes things will change
	Felt horrible	At video urodynamics
	Felt awful	The way her consultant spoke to her
	Motivated	Wants to get the problems sorted
	Wished	TVT had worked
Bladder treatment	Urodynamics	No benefit
	Video urodynamics	Had a big leak, felt horrible
	Physiotherapy	No benefit
	Drug trial	Migraines
	Inpatient retraining	No good as it was not a typical week
	TVT	5 months later everything came through again
		No help at all
		Wished it had worked
Concerns	Smell	
	Pads	Bulky like a nappy
	Feels dirty	
	Toilet mapping	
	Sex	Worried about being smelly
		Husband is usually okay but sometimes he wants to make love
		She agrees to try but then she can't

8th interview

Global themes	Organising themes	Basic Themes
Bladder treatments	Physiotherapy	Did not work before
		Not doing whole heartedly because they did not work before
	Drugs	Reactions with lots of drugs
		Prefers drugs to surgery
	Anticholinergics	Reactions- rash, diarrhoea, chest infection
	Duloxetine	Just started a few days before
		No side effects
		Looking forward to seeing if it helps
	HRT	Thinks it has helped nocturia
	Surgery	Hope she can avoid it with medication and exercises
Bladder symptoms	Nocturia	Improved
Emotions	Confidence	
	Hope	Looking forward to new tablet and consultant review

9th interview

Global themes	Organising themes	Basic themes
Other medical problems	Cancer	
Cause of bladder problems	Bladder damage during hysterectomy	
Expectations	Negative	I know there is no cure
	Positive	I know he cant cure me but he can help me
	Would like	To be able to go out
		To keep up with husband
Emotion	Less stress	Knowing there is no cure
	Shy	Withdrawn
Bladder treatments	Tablets	
	Surgery	Repeated
		Hoped for cure
		Did not work, needed oxybutynin
	Catheterisation	Tried for 10 days
		Did not like it

		Would only go out with her husband
		Terrified of catheter coming out climbing in and out of the bath
Restricted activities	Cannot not go down hills	
	Leaks with running	
	Cant keep up with husband	
	Cant fully participate with grandchildren	
	Going out	Always at home
Concern	Smell	
Comparison with other people	Old ladies on the bus	Smelling of urine
	Husband	She cant keep up
Coping	Carries items in her bag	Pads, knickers and tights
	Changes pad or underwear	To manage concern over smell
	Got a job	When determined not to give into cancer

10th interview

Global Theme	Organising Theme	Basic Theme
Emotion	Embarrassment	
	Depression	Because of lack of sleep secondary to nocturia
Cause of bladder problems	Infection	Loosing blood
Bladder treatments	Cystoscopy and bladder stretch	Okay for a little bit
	Tablets	Antibiotics
	Bladder retraining	Currently increasing times
Staff impressions	Negative	They don't tell you much do they?
		They don't seem to know what it is
	Comments	He wasn't pleased with something on the scan
Comparison to other people	Better	Mine is not as serious as some of them
		Another patient has worse problems

11th interview

Global Theme	Organising Theme	Basic Theme
Other people	Comparison	Brother wet the bed but she didn't
		Worried of ending up like the old ladies in the supermarket
	Secrecy	Worried she would get caught by a cleaner or caretaker when passing urine in a bowl
	Noticing	Work people noticed her frequency
		Work people noticed she was missing too often
	Husband	No patience, causing arguments
		He had helped her by making a device out of a lemonade bottle to help her pass urine in the lay-by
Emotion	Humiliation	
	Anxiety	
	Embarrassment	
	More positive now	
Memories	Childhood	Parents kept a potty and sponge in the car
		At school, put her hand up and was not allowed to go to the toilet
	Family events	Had to leave mother in law and father's funeral to find toilets
	Stranger	Knocked on a strangers door to use the toilet
	Travel	Leaking in an airplane toilet all over the floor
	Dancing	Dashing out from dancing
	Leakage	I remember it running down my legs
Cause of bladder problems	Childbirth	Tore badly
	Multiple operations	
Restrictions	Out of the house	Toilet mapping
		Cant go out
	Clothing	Has to wear skirts in case

		she has to nip behind a bush
		Cant wear nice underwear
	Sex	It affects your sex life. 'You don't feel sexy when you are padded up'
	Financial	Cost of pads. Used to wear toilet paper instead, which was irritating
	General	It has ruined my life really
Bladder treatments	GP tried things that made no difference	
	Retraining	No faith in it alone (better with tablets)
	Physiotherapy	Devices fell out and it was humiliating
	Not satisfied with anything before her current consultant	
Coping	Products	Takes clean pads and pants in her bag
	Devices/receptacles	Washing up bowl to void in after teaching a class
		Device from a plastic bottle to help going to the toilet outdoors
	Restricts fluids	
	Clothing	
Positive staff impression	Interest	It helps that her current consultant obviously has an interest
The future	Hope	Hopes to take long walks with trousers and trainers and not embarrass yourself
	Concerns	That she will end up like the old ladies in the supermarket
		Dirty, smelly, unclean

12th interview

Global themes	Organising Themes	Basic themes
Emotion	Unhappiness	
	Hope	To stop catheter and go back to normal

Symptoms	Wet and uncomfortable at night	
Staff impressions	Negative	GP didn't know what the treatment would be
	Positive	The nurses explained everything
		The doctor is pleased with me - that made me feel better
		Communication - I know what they are talking about
Bladder treatments	Physiotherapy	It was difficult when they showed me
	ISC	Difficult but got used to it. Accepts that, like everything, it has to be learnt.

13th interview

Global theme	Organising theme	Basic theme
Symptoms	Leakage	Coughing and sneezing
		Lifting children
Other people	Secrecy	Never told anyone for a long while
	Unwanted attention	The grandchildren and husband make a big thing of it
		My grandson said we had to stop running for the bus 'because nan's wet herself'
	Trigger for presentation	I came because the grandchildren joke and make comments
	Comparison	Granddaughter asked if I would smell like a lady on the bus
		Her mother ended up like this too
Treatments	Physiotherapy	No improvement
	Tablets	Side effects were a bigger problems than the incontinence
	Compliance	Does as asked but is no different

Avoids	Playing with children	In case of leakage
	Sex	In case of leakage – but no sex drive and neither has husband. Worries about this if his returns.
Future	Doesn't see things changing	

14th interview

Global theme	Organising theme	Basic theme
Comparison with other people	Mother	Leaked and couldn't stop
		Did not tell anyone
		Wanted to help her but she did not know
		Too shy to buy pads
		Stopped going into town
	Friend who had surgery	Suggested seeking help from the same consultant
Concerns	Age	Feels like an old woman
		Does things younger people do
	Sex	Used to have a problems but better now- not sure why
Emotion	Embarrassment	Seems to have got over the worst embarrassment
Symptoms	Leakage	
	Urgency	
Treatment	Physiotherapy	Exercises did not help
		Muscles are tight
		Daughters are physiotherapists
	Tablets	Helped
		Use them if going somewhere
		Was given something else - not sure what
	Surgery	Better to have when younger and healthier
		He (the consultant) does not think it would help
		Not bad enough for surgery
		Told it might make it worse

	Urodynamics	Lovely
		Very slick

15th interview

Global theme	Organising theme	Basic theme
Start of problems	After childbirth	
	Noticed a smell	
	Saw GP	Gave tablets for infection which did not help
Symptoms	Wet	
	? Incomplete emptying	
	Smell	Like ammonia
Coping	Gets used to situations rather than notice them	
Affected	Herself	
	Her relationship and sex	Pre-plans because of smell
		Not spur of the moment as baths and washes before
		Partner is used to it
Concern	Smell	
	Feels unclean	
	Other people	In case they can tell or smell it
Treatments	Pelvic floor	Okay
	Explorations	All normal which drives her mad
Emotion	Frustration over normal tests	Wishes something will show up so that something can be done

16th interview

Global theme	Organising Theme	Basic theme
Cause of problems	Childbirth	
	Age	Got worse with age
Start of problems	Controllable	
	Not severe	
	Nocturia	
	Became more aware of physical structure and that something was wrong	Because of pelvic floor exercises
	Initially a bowel problem	GP asked about the bladder

Self management	Restricts fluids	General
		Not drinking after 7pm
	Suppresses coughs and laughs	Does not always work
	Toileting	Goes to the loo properly before bed
		Goes to toilet before exercise- not effective
Restricted activities	Exercise	Needed to go to the toilet
		Would wet
		Jumping and moving around
		Accidents when out walking
	Coughing	I'd never dream of coughing
Feelings about bladder	Feels like her body is going to pack up	Doesn't want it to pack up
	It is vile	
	Always aware of the need to go to the toilet	
	It was desperate	
	Appalled	
	The beginning of the end	
	Feels like life is closing in	
	Feels old	Thinks things are designed to deteriorate from the age of 40 and not work much beyond 50 and she has reached that point
	Now feels that the bladder and bowel problems are interconnected	
	Not understanding why the bladder problems happen	
	Conditions at work are poor	Makes her feel more embarrassed and dirty
Emotion	Embarrassing	
	Unpleasant	
	Resentful	Having to live with the problem
	Angry	Cross, angry, negative
Treatment	Initially treated constipation	

	Pelvic floor exercises	Became more aware of physical structure and that something was wrong
	Advice	Told not to drink alcohol - not a problems
		Told not to eat fruit – a third of her diet which she really likes
	Without surgery	Things will get worse
		Would not feel human
		Would not want to be on this planet
		Anticipate a deterioration which she could not control
		Would not be able to go to work and she has to
		Shopping and visiting friends would become a chore
		Doesn't see the point of being around
		Would not feel useful in society
	Live with it (bowel problem)	Feels resentful being told this
Other problems	Bowel problems	Uncomfortable and unpleasant
		Bladder became secondary to bowel problems
		Reason for seeing GP in the first place but Dr asked about the bladder
	Bladder infections	Uncomfortable and unpleasant
Other people	Husband	Gets irritated with her
The future	Wants to lead a healthy life and not deteriorate	
	Doesn't want to wear sanitary towels and incontinence pads for the rest of her life	
	Doesn't want to be thinking about going to the toilet all the time	

17th interview

see following page

Global theme	Organising theme	Basic theme
Start of problems	Childbirth	Several pregnancies close together
		Weight gain
Bladder symptoms	Stress incontinence	
	Overactive bladder	Leaks if distracted
		Leaks pulling pants down, after a shower
	Worse at work	
	Told not emptying properly	Feels that when your mind is on other things you don't always think of the toilet
Coping	Tries to put it out of her mind	
	Showers at work	Has to pretend it is because of the heat rather than leakage
	Protection	Pads are uncomfortable and she doesn't wear them in the house
		Carries pads and pants
		Sometimes wears 2 pairs of pants for extra support
	Fluid restricts	Drinks more in the home
	Toilets	Preventative micturition
		Toilet maps
		Wont use public toilet paper in case of infection on the prolapse – carries her own paper
Restrictions	Sex	Leaks with sex
		Doesn't have sex because of pain
	Exercise	Cant play football with children
		Has frequency when she goes swimming
	Socialising	Has to find toilet before getting a drink
Treatment	Personnel	Initially saw GP
		Multiple hospital consultants
		Told by one that he couldn't do anything for her

	Surgery	Told she needed surgery - had 2 operations in one year (repair and colposuspension then a posterior repair)
		Expected surgery would sort out everything
	Tablets	Doesn't want to take prozac 'I wouldn't take that'
		I don't want tablets
Emotion	Embarrassing	
	Irritating	
	Relieved	Going to have more surgery
Concerns	Other people	Colleagues - she tells colleagues she is showering for heat, not leakage
		Children - cant play football with children
		Children ask why she is going to the toilet so often
		Patients - compares herself to patients for incontinence surgery and feels sympathetic
	Smell	
	Backache	Wonders if it is due to bladder, prolapse or wear and tear
	Prolapse	Worries it will get infected using public toilet paper

18th interview

Global themes	Organising themes	Basic themes
Emotion	Frustration	Time spent on problem - getting cleaned up, buying things
	Embarrassment	Buying pads but got better thinking that they may not be for her
	Anxiety	About cause of problems
		Anticipated problems in certain locations which

		made it worse
	Disappointment	Feels that life is not what she expected it to be
		About frequency
Symptoms	Worse in the daytime initially	Later became a problem at night
	Frequency	
	Leakage	
	Difficulty remembering stages	Relates this to not working and not having any markers
Exacerbating factors	Not using her brain enough at work/ in life	Not a lot to take her mind off the bladder
Restricted activities	Sunday walk	Was expecting to leak which made things worse
Treatment	Advised to wait 5 minutes in the night before going to the toilet	Did not want to do this in case she cant get back to sleep
	Tried staying awake in the night and setting alarm	No help
	Bladder training	Tried in the daytime but has other things she'd rather be doing and she doesn't feel she is a good candidate
	Lifestyle advice given at urodynamics	Not able to defeat the problem at a practical level
	Switched from coffee to tea	Found this beneficial
	Tablets	Thirsty and weight loss
		GP gave tablets but said he could not help otherwise and referred to hospital
Concerns	Secrecy	Cant be open with people
	Underlying medical cause	Worried in case of e.g. malfunctioning kidney
	Expense	Would rather spend money on the family rather than continence products
	Other people	May notice
		Not able to talk about the problem
	Pads	Don't always cope with

		the leakage
		Expense
	Age	Feels older than she is
	The future	Feels life is closing in/like there is not much time left
		Feels older than she is
		Thinks about physical deterioration
Coping	Pads	
	Limits caffeine	

19th interview

Global themes	Organising themes	Basic themes
Start of problems	Pain	
	Leakage	
	Theories of cause	Something pushing on the bladder making her go
		Bowel management makes bladder worse (increased fluids)
Bothered by	Lifting the Hoover at work	
	Urgency	
	Changing knickers twice a day	
	Other problems	Bowels - diverticular disease, pain in her left side
	Pain	Dragging pain goes right up her when she lifts or passes water
Treatments	Physiotherapy	Could not manage the 'pelvic floor thing' but does pelvic floor exercises when she can
	Inpatient retraining	Advised
	Toning tables	Does to tone her body but told it can help the pelvic muscles go tighter
Feelings	Displeased	'I don't like this, it never used to happen'
	Anxiety	10 years of anxiety and panic attacks in the past too
		Admits to not asking

		much because she was worked up.
	Expects bladder to be fine in the future	

20th interview

Global themes	Organising themes	Basic themes
Complaints	Incontinence	Leakage/ wet pads
	Uncomfortable	Right sided abdominal pain ?stones. Leg pain
	Itching	Inside and out
	Weakness	When passing urine
	Sex	Doesn't feel like anything when leaking and tired
Start of problems	Last pregnancy	
Treatment	GP gave antibiotics ?UTI	Allergic to antibiotics - 2 types
	On new tablet	Hopes it will work
	Physiotherapy	No help
	Self ownership	'Trying my best now'
Staff comments	Uncertainty	They not understand why my bladder problems
Emotion	Hope	Hopes tablets will work
		Hoping everything will be fine
	Anger	Shouts more around period time. Not controlling herself
Wants	To stop leakage	
	To feel comfortable	

Table 11.5 Thematic network for qualitative interviews (Group 1)

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Cause/aggravation of problems	Childbirth	
	Other	Other medical problems

		Emotion Unknown
Symptom related comments	Urinary incontinence	
	OAB symptoms (excluding UI)	
	Other symptoms	Bowels Others
Emotions	Positive	
	Negative	Embarrassment Anxiety/concern/conscious of problems Anger/frustration Depression/unhappiness Other – general Dread Vulnerability

		Distress
Treatment	Positive	Clinical staff/ communication Clinical staff/ other Treatment specific – tablets Surgery ISC General Future concerns
	Negative	Surgery/ catheters Physiotherapy Bladder retraining Negative statements/activities by staff/situations Dissatisfaction with service

		Physiotherapy
	Future	
	Matter of fact	Physiotherapy Tablets ISC Surgery Lifestyle Bladder retraining
	Other	
Concerns/ preoccupations		Toilet mapping
	Other people	Dependency/ burden Friction Self conscious Comparison
Conscious/ self image	Concerns	Smell Age

		Hygiene The future – negative, positive, unsure Victim
Coping	Pads	Positive Negative Other
	Distraction Fluids Articles Ability to cope Others	
Sex		
Restricted activities	Restricted activities	Going out Exercise Living activities Others

		Travel and transport Life in general

11.4 Conclusions

A wide range of themes emerges through these qualitative interviews. A full detailed analysis with text segment illustrations is in Appendix VI. These themes will be used in development of the treatment-planning tool in the future.

CHAPTER 12

MAIN STUDY

GROUP 2

12.1 Introduction

Chapter 11 clearly demonstrates a wide range of issues and themes experienced by women with UI. This study wishes to focus on surgical management of SUI. The first group of patients presented in Chapter 11 were women with a history of UI. They may have had SUI, MUI or OAB and may have undergone surgical, medical, conservative or other treatments or a combination. Group 2 contrasts, in that all 20 women have, at some stage, undergone surgical management of SUI. There are a variety of surgical treatments for SUI with the most established being colposuspension and more recently TVT. These women may have undergone one of these procedures or even both, they may have had a different SUI operation, their surgery could have been recent or many years ago. The clinical details of their surgery and their demographic details were not collected. The focus was on the women's recollections of their own experiences, nothing else. These women were still attending the continence services and therefore are likely to have ongoing continence problems. They are not, therefore, likely to be a representative sample of

postoperative women. They are, however, a rich source of information on experience of treatment. These women each underwent a repertory grid and a qualitative interview.

12.2 Repertory grids

- **Subjects**

As described in Section 12.1.

- **Design**

The repertory grid technique was customised to study women with UI through the initial pilot stage of action research. The grid completed by this group, shown in Figure 12.1, was modified slightly to take account of the fact that the women had all had SUI surgery in the past.

Figure 12.1 Blank repertory grid for study group 2

Elements→ Bipolar constructs	Me before the problems started	Me when my problems were at their worst	How I expected to be after surgery	How I hoped to be after surgery	Me now, how I am after surgery	*Element chosen by subject. Something I would like to do that I could not do before*

						because of the problems
Bipolar construct formed by comparing and contrasting elements marked 'O'	O		O		O	
	O	O	O			
		O		O		O
			O		O	O
	O			O		O
		O		O	O	

- **Procedure**

As in Group 1 each subject is presented with the elements in groups of three and asked in what way are two similar and the third different. This is repeated for different combinations of elements to elicit six bipolar constructs. The bipolar constructs for each patient undergo thematic analysis.

- **Results**

The thematic network for the constructs of each subject's repertory grid is illustrated in Table 12.1.

Table 12.1 Thematic networks for individual repertory grids (Group 2)

1st postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Mood	Anxiety	
	Crabby	
Restriction	Restriction	
	Able/not wanting to go out of the house	
Symptoms	Incontinence	
Preoccupation	Considering toilets all the time	

2nd postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Self-image	Normality	
	Confidence	
Symptoms	Leakage	
Emotions	Unhappy	
	Upset	
	Tense	
	Satisfied	

3rd postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Emotion	Unhappy	
	Disappointed	
	Hopeful	
Self-image	Normal/abnormal	
Restriction	Job	Interfering with job
	Exercise	
	Not able to lead a normal life	

4th postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Self-image	Abnormal	

Symptoms	Leakage	Incontinent
		Needing protection/pads
The future	Expectation of success	
Emotion	Don't like	
	Depressed	

5th Postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Restriction on lifestyle	Fluid intake	
	Need for preparation	
	Pads	
	Activities	Walking
		Laughing
Negative emotions	Negative impact	
	Confidence	

6th Postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Emotion	Happy/unhappy	
Symptoms	Leaking	
	Nocturia	
	Urgency	
Restriction	Able/not able to go out	

7th Postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Affecting freedom	Mobility	Free to come and go
	Planning	Having to plan everything
	Socialising	Affecting social life
		Not able to stay with people overnight
	Employment	Not able to take any job
	Not able to make a commitment	Not able to a join residents committee

8th postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Freedom	To go out	Able to go out without pads
		Planning to go out
	To socialise	Able to go visiting friends

	In general	Free/not free
Symptoms	Leakage	
Pads	Needs pads to go out	

9th Postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Limitations	Activities	Not able to run around/cough/sneeze
	Having to wear a pad	
	Having baggage (e.g. pants)	
Comfort	Feeling uncomfortable	
Feelings	Expectation/reality	
	Normality	

10th postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Symptom	Leaking	
Emotion	Uncomfortable in myself	
	Unhappy	Unhappy having intercourse
	Concern	Expecting a complication
Treatment	Negative expectation	Expecting a complication
Limitation	Sex	Unhappy having intercourse
	Social	Not mixing socially

11th postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Preoccupation with bladder	Thinking about the bladder	
	Thinking about where the toilets are	
Problems	'Lots of problems'	Not specified
Restrictions	Clothing	Not able to wear skirts
	Time	Not able to sit through a meeting

12th Postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Self-image	Age	Younger/older

	Normality	Walk at a normal pace
	Self worth	Feels appreciative
Activity	Walking	Able to walk….
	Volition	Feels like doing things
Emotion	Elated/dread	
	Feels appreciative	
	Good/bad	
	Motivation	Feeling like doing things

13th postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Emotion	Anxiety	
	Unhappy	Unhappy about bladder
Confidence	Confident / not confident	
Treatment	Did not know	Thought I had to just put up with problems
	Expectations	Expected immediate success but had complications
Bladder	Bladder takes over life	

14th postoperative grid

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Emotion	Disappointment	
	Despondent/hopeful	
Social	Reclusive/ outgoing	
Bladder	Leakage	Predictable/unexpected leakage
	Thinking about bladder	

15th postoperative grid

GLOBAL THEMES	ORGANISING THEMES	BASIC THEMES
Normality	Normal/ not normal	
Emotion	Happiness	Happy/ not happy
	Negative	Worried/ anxiety
		Mentally negative
Problems	Problems/no problems	

16th postoperative grid

GLOBAL THEMES	ORGANISING THEMES	BASIC THEMES
Symptoms	Leakage	Leaking
Negative feelings	Awful	
	Frustrated	

	Not good	
Sex	Not able to have sex	
	Feeling bad for my partner	
Other people	Feeling bad for my partner	

- **Conclusions**

Many themes have been identified through this analysis for use in the treatment-planning tool.

12.3 Qualitative interviews

- **Subjects**

As described in Section 12.1.

- **Design**

Qualitative interviews were performed with these women. The design of the interview was the same as for Group 2. The interviewers aim was a free flowing interview with minimal input from the interviewer.

- **Procedure**

The women completed written consent before their interview. They were interviewed as previously described in Chapter 11. The interviews were handwritten and typed up after the interview was over. The interview text underwent thematic analysis as in Group 1. Saturation of themes was being reached during the analysis. For this reason the first 16 interviews underwent full thematic analysis but the remaining 4

patients transcripts were read looking for any new themes. Virtually no new themes were discovered but useful examples and text segments were extracted and included in the interpretation of the thematic network as represented in Chapter 15.

- **Results**

The results are illustrated in Table 12.2.

Table 12.2 Thematic networks of individual qualitative interviews (Group 2)

1st postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Emotion	Frustrated	Gets worked up
		Gets frustrated with herself
	Panic	Panics to find a toilet
	Depression	Up and down emotionally
		'Postop blues' 1 week after any surgery
Symptoms	Frequency	
	Leaks with coughing	
Restrictions	Activities	Cant lift anything heavier than a kettle
	By symptoms	By frequency
Expectations after surgery	No more leakage	
	Not changing pads	
	Not wearing panty liners	

2nd postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Presentation	Not because of bladder	Because of bleeding
Treatment	Exercises and physiotherapy	Helped a bit
	Surgery	Told she may as well have incontinence operation along with hysterectomy as she

		would probably need it in a couple of years
		Was fine for a couple of years after surgery
		Postop was not emptying bladder properly - ISC
		Advised a further operation (vaginal repair- voiding difficulties since)
	Future	Would have a further op if there was 70% chance of no pain and slight leakage
	ISC	Became sore and needed urethra widened
	Suprapubic catheter	Seemed least drastic
		Not ready for something permanent
		Not too obvious - work colleagues will tell her if it is obvious
		Allowed to decide for herself
		Complicated by infections - was not prepared for that
Care	Her own role	Allowed to decide her treatment re catheter
		Not realising UTI with ISC 'I am not a medical person'
	Not prepared	For UTI with ISC
	Anxious	Nervous about attending
	Self-conscious	Does not want people to make a fuss
	Communication failure	Was not told what she needed to order when discharged. Her niece (a district nurse) advised her
		Getting through to the GP is difficult
		GP could not find urine results
	Good	Catheter company is

		good and discrete

3rd postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Symptoms	Incontinence	Leakage
	Lack of control and leakage	After TVT
Care	Private	Went because GP said it would take a long time on NHS
	Went NHS after first consultation	Found it was quick
	Continuity	TVT cut by someone other than the initial surgeon, or at least he didn't speak to her
	Follow up	Told to be seen in 6 weeks but not sent appointment. She had to phone to make appointment
TVT	Stopped leakage on coughing	
	Still had lots of leakage and lack of control	
	Had TVT cut	By someone else – didn't speak to her

4th postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Symptoms	Leaking	With coughing, sneezing and laughing
	Thrush	Gets thrush all the time
Treatments	Tablets	Tried lots, none worked
	TVT	Complications - postop retention
		Abdominal pain
		Tape erosion
	Catheters	Preferred suprapubic. Easier to cope with. Other catheter caused infections
Complications of TVT	Pain	Was an ovarian cyst
	Erosion	Ripped husband to pieces on intercourse.

		Told it was scar tissue and given anaesthetic cream and tablets. Second opinion found the erosion. After tape was removed she still had pain on intercourse, groin pain and worse leakage (expected)
Emotions	Depression	Feels very low (cried)
Self-image	Age	I am a 43 year old woman and it doesn't look good
	Normality	It's not right is it?
	Sexuality	I am not a proper woman. I can't give my husband what he wants (not able to have sex for 11 months)
Staff	Dissatisfaction	What he says today is not good enough; I want to get back to work.
Restriction	Job	Checkout operator - wears towels and goes to the toilet all the time
Pads	Expense	Were costing a fortune but getting a social worker and district nurse to come out
	Secrecy	On holiday did not want cleaners to see pads in her bin in her hotel room so she put them in other bins
Care	Ovarian cyst	Feels it should have been picked up before
	Retention	Was warned that this could happen
	Erosion/dysparunia	1st assessment was just given cream and tablets and told it was scar tissue - took 2nd opinion to find erosion
	Catheter	Wished she had the suprapubic as she found it easier to cope with

5th Postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Care	Negative care	Waiting lists
		Waiting times
		Changes of consultant
		Changes of medication
		Consultant in NHS rushed
		Not told what to expect postop
		Felt anxious waiting 8wks for review
	Positive care	Ward staff showed respect drawing curtains
		Clinic staff showed respect for privacy
		Postop review - everything explained, feels more positive
	Self input	Private care - faster pathway
Impact of bladder	Restriction	Holds her back
		Fluid restriction for travel
		Walking dog
		Work - travelling
	Emotion	Degrading
	Symptoms	Discomfort when holding on
	Other people	Treat it as a joke
		Only husband understands how it has impacted
Coping	Planning	Makes sure there is a toilet
		Fluid restricts for travel
	Other people	Treats it as a joke
	Emergency	Voids behind a bush

6th postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Cause of problems	Childbirth	Hysterectomy
Impact	Restriction	Toilet mapping
	Affected family life	
Coping	Just got on with it as a mum	
	Fluid restriction	Could not go out if she drank
Treatment	Satisfaction with personnel	Could not fault anybody
	Tablets - negative	Felt sick and reduced quality of life
		Did not want to take one which was an antidepressant
	Surgery – positive	Can cough, laugh, drink
	Surgery – negative	Still has urgency and urge incontinence
		Has to do ISC – no facilities for this at work

7th postoperative interview
I

GLOBAL THEMES	ORGANISING THEMES	BASIC THEMES
Bladder problems	Urgency with leakage	
	High capacity, holds on too long	
Cause	Holds on too long	
	Drinks too much	
Effects	Leaks	
	Wears pads for peace of mind but usually dry	
	Tests herself	Holds on to test herself
	Psychological problem	As soon as she goes out
	Restriction	Affected psychologically as soon as she goes out
	Leaks in the night	If very tired
Treatments	Physiotherapy	Exercised too strongly and too often
		Helped initially
	Surgery	Expected to hold on and leak less often – not so. Wears pads
Psychological effects	Self challenge	Tries to hold on as long

		as possible - putting herself to the test
	Knows there is a problem there	
	Wears pads for peace of mind	Even though they are rarely damp

8th postoperative interview

GLOBAL THEMES	ORGANISING THEMES	BASIC THEMES
Symptoms	Severity	Life is a nightmare
	Stress leakage	Cough sneeze walk
Emotion	Negative	Life is a nightmare
		Felt negative towards physio and their treatment
		Felt physio was laughing at her
	Hygiene	Will not do ISC in public WC
	ISC mental block	Friend told her she could perforate her bladder
	Feels restricted	Wont do ISC in public WC – wants indwelling catheter
	Fear of being alone	Does not like being alone – preferred waiting room to consultation room when waiting for consultant
Treatments	Hysterectomy and bladder repair	Helped for a bit
	Continence advisor	Bladder scans and referred on
	Physio	Felt they were laughing at her – stopped going
		Made her feel bad
		Given treatment to do at home – stopped because of the way it made her feel
	TVT and post repair	Felt prepared. Knew risks
		Unable to pass urine postop. Prolonged catheter and then ISC

	ICS	Friend told her she could perforate bladder
		Family member had cancer
		Mental block with ISC
		Four admissions
		Caused burning, urgency and leakage
		Did it when she had urge to avoid a leak – seven times a day
		Would not do it in a public toilet. Fine at home
		Wants an indwelling catheter instead so she can have more freedom and to avoid discomfort and pain
	Detrusitol	No help yet – only two weeks
	Cutting tape	Planned. Hopes it will improve things

9th postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Start of the condition	Cough	Leaked
		Thought cough had caused the damage
Emotion	Embarrassed	
	Worried	In case leakage happened outside the home
	Confidence	Wore protection to feel more confidence
Coping	Protection	Pad and hand towel under pyjamas
		Towel on the bed
		Bath towel on other friends sofas
		Tampon and sanitary towel if going out
	Voiding	Goes to the toilet all the time if going out
Care	GP very understanding	
	Consultant -	Lay on bed and leaked.

	embarrassing	Had internal
		Told ideal candidate for internal
	Urodynamics	Description. Had it a few days preop
	TVT	Had leaflet. Decided to go for it
		Found it great
		Local anaesthetic, never felt a thing
	Postop	Difficult to pee
		Surprise at blood loss – was not explained to her
		Sore for 3 or 4 days
		Missed 3 or 4 days of work
		Missed out on her birthday
	Review	Saw consultant at private consulting suites
		Everything was fine
		Asked to cough and didn't pee which was amazing
	Six months later	Told there was a postop study but didn't hear anything
	Recently	2 or 3 infections
		Normal cystoscopy
		Frequency
		Feels like there is something waiting to come out of the urethra

10th postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Emotion	Embarrassment	Too embarrassed to speak to anyone
		Urodynamics was embarrassing
		Staying in hotels and sheet being wet
	Upset	Got upset when telling GP about problem with bladder
	Anxious	Consultant treatment

		was nerve wracking at the beginning
		Physically I was okay, just the thought really
	Happy	After treatment to stay in hotels
Avoidance	Social	Avoided invitations
		Avoided staying in peoples houses in case she wet the bed
	Sex	Avoided intercourse with husband
Life	I wasn't having a life at all	
Presentation	Went with swollen feet	GP prescribed gym but she couldn't go because of bladder
	GP said she should have told as there is a cure but they don't know how good it is but something has to be better	
Treatment	Physiotherapy	Told her improvement was limited
	Consultant	Nerve wracking at the beginning
	Urodynamics	Embarrassing but the girls were great
	Postop	Lovely
		Doesn't have to plan things ahead
		Felt okay for the first time
		Happy to stay in a hotel with women cleaning the beds without embarrassment
Protection	Pads	Wore heavy pads
		Had to carry pads all the time
		Changed them every 2 or 3 hours
		Pads and clothes would get wet

11th postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Presentation	Assumed there was not other treatment than physiotherapy	
	So many adverts for pads	Assumed there was no other treatment
	Thought C/S would prevent these problems	'Silly me'
Symptoms	Frequency	Going too often
		Could not leave house without going to the loo, sometimes even twice
	Urgency	Key in the door
		Walking uphill
		Getting off the bus
		Standing up at work
		Getting out of bed
Management	GP	Gave leaflets
		Made referral to hospital
	Urodynamics	Embarrassing
		Tubes and wires
		Had to have it before physio but met another women who could have physio without urodynamics
	Physiotherapy	I knew about pelvic floor exercises
		Went for months, improved but not enough
	TVT	Not able to have colposuspension because of 4 c/sections, too much scar tissue
		Op was a doddle – best op I ever had, could not believe when it was finished, better than having a tooth out!
	Postop	Reduce frequency
		Able to get out of bed (without urgency)
		Amazing what a little bit of tape can do 'to get your life back'

Coping	At work	Would have to stand and wait to get bladder control before she could move
Emotion	Embarrassed	By urodynamics
		'Anything to do with women is embarrassing'
	Horrible	
Restrictions	Clothing	Could not wear a skirt ' a wet patch on a skirt is obvious for miles'
Other people	Boss	Would stand at the door and say 'are you coming' while she was trying to get bladder control
	You don't want anyone else to know	
	Mother says 'you're too young'	
	Daughter says 'you have more wrinkles than Nan', and it is true	
Age	Mother says I am too young	She has only started leaking
	Has more wrinkles than her mother	

12th postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Treatment	Surgery	I have to believe it will work
		I have to trust the person doing surgery
		I wasted time not having surgery sooner
		Surgery was very good
		Anaesthetist was very reassuring
		I did try everything other than surgery. I suppose you have to do that. I did come in positive that it would change my life and it has
		I had it when I was off

		work and not have to tell people what you are doing
		ISC - I was worried I would have to do catheterisation. She gave me a couple of lessons in that
	Local anaesthetic	I was lucky to be a day case having just local and sedation. Within an hour I was having a cup of tea. That was nice.
		You don't have that sick woosy feeling. I am glad I opted for that because I felt much better. Went home at 7 o'clock
	Self catheterisation	I hoped I would not need it
		Tried it before - made me determined that I would not need it
		She did her best to reassure me it would only be for a couple of months - which helped
		That is the worst thing. Coping with living and then have to self catheterise
		It is not a pleasant thing to have to do is it?
	Expectations	I was told I would be improved but I wanted a cure
		I came in positive that it would change my life and it has
	Postoperative behaviour	I feel I have been cured
		I always wear trousers
		I chose not to drive but it drove me mad. Husband drove me everywhere – I hate it
		I am a lot happier. It really makes me happy
		I feel I waited so long

		and put up with a lot of things so long. I think it is unnecessary to do that. It is a waste of time putting up with all that.
		I joined a slimming club. I am doing well
		I want to get on with my life and do things
	Urodynamics	Not unpleasant
	Injection	I don't know what it is – like collagen
		I was referred here for them when I got here they didn't want to do them and I tried the drug trial
		They did not think it would give the desired results and would have to be repeated
	Stem cells	They are doing something now on stem cells. Would not then have to have the operations
	Pelvic floor exercises	Physio said I had a better pelvic floor than her. I could do pelvic floor exercises
		They did improve it but not a cure
	Cones	I have tried weights. They are alright but did not solve the problem
Start of problem	Can not remember	It is so long
		GP probably sent me to physio or urodynamics – cant remember
	Cause	I did have big babies though
	The hysterectomy helped a bit	I had endometriosis. I don't know why I had it really
Symptoms	Effect your life	More than you realise until they have gone
	Long duration	Years - 20 or more
	Leakage	Picking up child

		At work
		Crossed legs to sneeze
		Walking - even slowly
		Jumping out of the way of a car
		Laughing, coughing
		Picking up things in the supermarket
		Running for a bus
Effects	Clothing	Never wore trousers - hot and sweaty
		In a skirt you can change your clothes
		Extra clothes to go on holiday
		Carry spare knickers
	Pads	Carry spare pads
		Leakage would go beyond a pad. It was horrible
	Exercise	Leak with exercise so don't exercise so put on weight
	Limited	Cant do things you want
	Toilet mapping	
	Nocturia	
Emotion	Lethargic	Because you cant exercise
	Postop	I am a lot happier
		I just feel great. I really do
		I did come in positive that it would change my life and it has
	Secrecy	Had op when not working so as not to have to tell people
		Did not want to explain to insurance company want it is – apparently it does not fit into their classification
Other people	Patients - When you come into hospital you realise other people are worse off than you	Other patient had pigs intestine used. I was lucky to be daycase having just local and sedation

	Staff	The anaesthetist was reassuring
		I could hug him (surgeon). I think it is just wonderful
	Others	Not tell them what you are having done

13th postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Surgery	Complications of colposuspension	Mr___ explained the complications. I had every one of those complications on the green sheet
		It was very stressful and anxious
		I has a pubic catheter and was keeping charts at home
		My wound split open and I came to hospital every other day to get it dressed - not a nice experience
		I had the bag and was clamping and unclamping it myself
		I had to learn to self catheterise - I did not like that at all
	After recovery/ now	I have a prolapse, the womb and bowel has collapsed
		I have irritability. Plan everything around the toilet and be careful with what I drink
		It is one thing after another
		The operation has worked
Other people	You don't go telling people	You feel abnormal
	Only when you talk about it do you realise how many people have	

	it	
Symptoms	Stress incontinence	I had a bad cough and could not cross my legs when driving
Seeking help	I thought there was nothing which could be done	
	I thought I can put up with this the rest of my life	
Emotions	Complications – it was very stressful and anxious	
Self-image	Normality	You feel abnormal

14th postoperative interview

GLOBAL THEME	ORGANISING THEME	BASIC THEME
Surgery	Stress incontinence op	Successful
	Staff	The operation was done by a doctor who was about 10 years old!
Start of the problems/cause	Epidural	I was encouraged to have an epidural. Unable to pass urine after this. Was catheterised and stayed in hospital for 7 days
	Childbirth	I believe the problems stemmed from the way she was born or the epidural
	Hysterectomy	After the hysterectomy it became even less of a controllable problem
Presentation	Other problems	Back problems since delivery, which had worsened. Niggling tummy pain which would build up until I was sick
		Doctor had to come out and give me an injection
	I was made redundant because of ill health	
	Fear for the future	When I am 77 I don't want to be walking around with wee marks on my stockings

Psychiatric	GP at one point suggested it was all in my mind	
	I was referred to a psychiatrist	
	Went on cognitive psychology for the pain	Instead of picking lots of spuds pick up a couple and relax and enjoy the garden
		It is different to the way you work, it was most helpful being in the company of other people
Staff	Doctor	Lovely Dr with brown eyes
		He said 'I am going to insert 2 fingers to test things' – how can you take that seriously!
		When you go to see a specialist you expect they know what they are doing
		He told me I was going to have the vagina of a 40 year old – I asked him 'how is anyone going to know? With a mirror?'
		He asked the female trainee 'what do we say?'. She looked surprised and he said 'dry mouth, dry knickers'. I did not understand
	Hospital	I think this is one of the best. My mother spent time in other hospitals – they were unpleasant, uncaring and dirty
		If I needed anything done I would go to the vets or here! It has a nice caring feel. It is nice to feel people are going to look after you.

		When my mother was in hospital people died and no one noticed until I told them and I was offered counselling
	Communication	No one tells you (the operation)
		Fluid advice – no one ever told me
		Difficult to know how much people understand. They think you understand but you don't. I think it would be nice to have the understanding that you may be left with urge incontinence.
		Medical people may not listen because they have heard it all before
		It would be nice if people had longer to listen
		I saw a chap speaking in tongues. Shouted at me that I should not be drinking decaf tea. I had lost my job. I cant even have a bloody cup of tea
		He used the term 'maxed out'. I am 57, how can you presume that I know what maxed out means
		Women talking to women might be more beneficial
		An informal atmosphere might be more beneficial
		When you come into hospital people don't have time and are busy. They have to listen. I think medical people think ' you have got this and we can do this'
	Bladder drill	Found difficult. Needed

		to go to the toilet within 15 minutes of drinking
		Made a big difference
		I am giving the bladder drill the best shot and if things stay the same I will manage
		Didn't know what to do the first day – felt they had wasted a day
		For all I knew it could be marching up and down the ward
		There was a feeling on the ward that not all the nursing staff were enthusiastic about bladder drill
		I found the week extremely tedious. It was difficult to do and very hot
		The following week I was virtually in tears. I had to talk to myself. I was too keen and tried to relax. I reaped benefits from it
		There was another lady in, worse then me. I was with her all the time. By the end of the week she was a bit better and I could see that it does work
		I was told to wear pads but I threw them away – I saw them as a step backwards
	The nurse clinic is good	They have more time to explain thing to you. Not so pressed
	Fluid advice	Tea and coffee made a big difference
	Ring pessary	They gave me a ring which was not successful
	Talking to others	I talked to the ladies in

		the waiting room and found that I should count my blessings
		Talking to other people with similar problems is a huge benefit
		While I was here for bladder drill I talked to other people, one or two had problems
		There is a terrible stigma. I have a friend who regularly hops onto the sink – I wish I was light enough to hop onto the sink
		Stick everyone in a room and be late and we are forced to talk to each other. I have realised that medical people sometimes don't have the answers
		I think sometimes there are things women prefer telling women. Talking to women might be more beneficial
	Surgery	I don't know what operation it was, cause no one tells you
		Then I realised with a Burch colposuspension you can get urge incontinence instead of stress incontinence
	Tablets	I tried tablets but got a dry mouth. I decided to put up with it
		I got reflux and acid coming into my mouth
		I could not even pass water, didn't even want to - I rang the national patient helpline. Referred to hospital – told it would resolve when the tablets wore

		off and it did
		I felt cheated because I thought they were going to be the answer
		Dr suggested I took the time release ones. I did not feel confident to do it
		I am always very reluctant to take tablets
		Conscious there may be side effects – ran out of prothiaden yrs ago and was up the wall
	Patches	I asked if I could try patches. I felt rejuvenated by it- they slowed down bowel and bladder
		I thought I may go back to work
		I had a reaction to the patches
	Talking	Talking has been the most enlightening thing. Tea and coffee alone have helped me
Bladder	Control	It was a controllable problem, then it became less controllable
	Predictability	At least with stress incontinence you can cross your legs. With urge you have no idea when it will happen
	Sex	You could rarely have sex because you will wee
	Urgency	Key in the door - could not get in. Weed and pood in the garden
	Work	Thought I might go back to work as the patches were helping
Coping	Potty under the bed	Downstairs toilet taken away
	Other receptacles	Margarine tub/ weeing in the garden
	Bladder drill	I hope it is not the good

		weather but the bladder drill that is helping
Thoughts	Bladder on mind in the mornings	Cant walk well and get to toilet in time
	Worry	My bladder is an absolute worry to me. I am a martyr to the pain and my bladder
		I am concerned what is going to happen to me in the future
Effects of other problems	Mobility	Cant get to toilet in time
	Bowel and back	Between the bowel, bladder and back my life is a misery
		If my back got worse I would go downhill with my bladder. I would be happy to make the loo 8 times out of 10
	Pain	I am a bit concerned because of this pain
		Thought pain was related to not being able to pass water – low grumbling pain
	Job	I had lost my job

15th postoperative interview

GLOBAL THEMES	ORGANISING THEMES	BASIC THEMES
Feelings	Vulnerable	
	Worry	About having to put tissues in when walking
		About no urge to have sex postop
	Felt low	
	Cant cope	Has learnt to rise above it
	Self blame	If I was stronger, more confident, happy person. Didn't ask questions
Symptoms	Stress leakage	Walking, star jumps, trampoline
	Looking back I don't	

	think my bladder was that serious	
Protection	Tissue paper	When walking
Effects	On travel	Had to keep stopping
Coping	Fluid restriction	Felt I needed water to keep healthy
	Feels she cant cope	Has to rise above it. I have learnt I am not going to wake up and it has gone
	Sometimes puts tissue in	Just in case I might leak
Referral	Contacted Bupa because she had it anyway	Advised to contact GP
		Sometimes I wish I didn't have Bupa. If I had been NHS I don't think they would have done surgery first
	GP	Advise pelvic floor exercises
	Self request	I requested to see someone specialised
	Other people	
	Consultant	Was very nice
		Didn't explain alternatives
		We tend to put doctors on a pedestal
	Different consultant	Warier of encouraging the operation unless they really have to
Treatments	Operation	Consultant suggested TVT straight away. Told me it would be amazing, change my life. Not like the old days. I would be out the same day
		It all sounded so simple. Because he was recommended I believed him. I went along with it. Didn't get any other options
		I didn't ask questions. I thought a week off work, time off and attention

		from my husband, some respite
		Alternatives – I believe there is physiotherapy exercises, cones and uninvasive surgery. If he had explained what a good and bad bladder was - I was in the middle
		There was nothing he said which made me feel afraid of surgery. If I had been aware of things I don't think I would have had it
		Problems. Late going down and had to stay overnight. Very sick the next morning. Feeling sick and distressed. Was there for 3 to 4 days. Sent home with a bag. Woke up with excruciating pain. Almost fainting. Sent to hospital – UTI
		It was a long process – I thought 'Oh my God. What have I done'. Lost weight. Stayed at home for a couple of weeks. Did what I was told. I wasn't exercising so I suppose it wasn't at its worst
		Started getting back to normal but still got cystitis, antibiotics, stinging pain. Took antibiotics – didn't get better
	Suggestions	Would have liked more information
	Postop review	Told everything was fine. Felt the tape was okay. They said they would check.

		(?Cystoscopy) Everything was normal. I felt demoralised after that 'do they think I am exaggerating?'
	Tape cut	Had a second opinion and videourodynamics. Had the tape cut which was upsetting. I was hoping I would not have that pain again but the next morning it was there. I was told to give it time there would be bruising
		Lost any urge to have sex. It wasn't brilliant before but it was worse and that worried me
	Expectations	I was expecting something miraculous but I didn't feel that
	Urodynamics	I did urodynamics where you jump up and down; he said I was fit and healthy which should help
Comparison with other people	My mum had problems and was not successful	Because I am fit and my muscles are strong there should not be a problem
	Sister had electrodes inside which helped	
Sex	No urge postop	Not great before
		Worried about this
	Last flare up was after sex	
	Separated but worried if she gets back with her husband she wont be able to have sex	
Holiday	Bladder much better	I think it may be related to stress
Exacerbating factors	Stress	Better on holiday
	Lifting	Intensifies it (pain)

16th postoperative interview

GLOBAL THEMES	ORGNISING THEMES	BASIC THEMES
Cause	Childbirth	Twins. Everything collapsed inside and I was leaking
		Told I could not get pregnant and if I did they would terminate it so they sterilised me
Surgery	Six surgeries	Including the TVT and the colposuspension
Medication	Oxybutynin	Was in a trial. And gave me headaches
	Duloxetine	Didn't work
	Never prescribed medication by GP or urology	
TVT	Good	Worked 100% for a year
		I thought 'this is it'
	Bad	I started leaking again (after a year)
Staff	Consultant	He always makes sure you have as good a life as possible. He never gives up. Never says 'I cant do anything more for you'
	Nurses	They never give up
Worst aspect of treatment	ISC	Worst thing was going to self catheterise but I know I don't have to
Inpatient treatment	Proved that it was well worth it	I don't mind what treatment I have – I'll take it
Hygiene	Baths are important	You feel cleaner
	You are always using wipes	I never go anywhere without wipes
Other problems	Cognitive	Difficulty spelling. Add letters onto the ends of words
		It is like some of my brain cells have gone with the seizures
	Epilepsy	I fell from the top of the stairs – I think it is safer to have them outside
	Bowels	Ulcerative colitis – has to wear pads for faecal

		incontinence
	Emotional	Crying because of leakage and having to change in public toilets
		Felt awful. Not having a drink on a night out on holiday – people were looking over
Coping	With cognitive aspects	I lead a subcommittee of 10 - people to keep this mind
	Leakage	I have worn pads
	Mints	I need mints. Instead of drinking
	Spare clothes	Under desk. Carries spare clothes
	Void before a meeting	In bladder training they say 'don't go just in case'
	Restricts fluid after six	Even if I had a bit of drink I would wet
	Carries wipes	For hygiene
Effects	It has affected my whole life	I have not let it upset my life
	Holiday effected	I didn't allow it to spoil, because that trip was arranged as a surprise for my 60th
Symptoms	Uncomfortable	
	Sore	
	Always wet	
		Whole bladder was emptying
		Wet the car seat
	Urine infections	Every month and became allergic to antibiotics
Surgery	Vaginal repair	Aged 29yrs
	TVT	
	Marshall Marshetti	Made everything worse
		I think I was a Guinea pig. Only 6 of us in the country. It was a sling. I think if it was a normal repair it would have been better
		The women who have

		had these have had problems
	Colposuspension	Sex painful afterwards
Sex	Not affected	I have not let it affect my sex life. I am on my 3rd partner
	Previous partners	My first husband was not a very loving man but he was sexual
	Current partner	The man I am with is very loving and I would like to have sex
	Not able to have sex	Cant have HRT because of antiphospholipid syndrome. Tried Replens and KY jelly
		Colposuspension made things worse. Tried sex once but it was very sore
Other people	Friends	Say 'oh, are you going into hospital again for your bladder'
	Comparison	There are lots of people worse than me
		I worked for Samaritans and a Crohns group
		My friends have had colostomies and my daughters' pregnancy losses
		Other patient wont go out – I refuse to stay in because of it
Other issues	Inherited problem	The black mark in life is that I have passed this antiphospholipid to my children
		At least now her sisters family can be tested and there are scans for pregnancy
Pads	Wearing pads all the time	
	Not able to wear trousers	Because wearing thick pads
	Expense	Pads cost a fortune

		Daughter, a district nurse, got her a big box of pads and a kylie mattress
	Got pads to go to Disneyland and saw consultant at the airport	Things like that is what happens
Clothing	Had to wear skirts	When she liked wearing trousers
	Have to carry spare clothes	
	Under work desk	Keeps spare shoes and tights
In public	Getting caught out on the bus	Not so bad in a car
	Witnessed getting caught out just before a meeting	Had to change clothes
In car	Not as bad getting caught out as on a bus	
	Wet car seats	Took 3 days to dry out
On holiday	Wet sheets	There was a thing on the bed so it didn't go to the mattress. Took the sheet off, washed and dried with hairdryer
	Fluid restricts	Can't have a drink after six. Partner drank 3 pints and I had to sit with nothing in front of me. Felt awful
Going out	Leakage	It is when you are out and get caught out
	I refuse to be kept in	

To summarise, the global themes, emerging from the combined analysis, described in full in Appendix VII are:

- Emotion
- Cause of the problem
- Effects of other problems
- Start of the problem

- Symptoms
- Restrictions
- Presentation
- Treatment
- Care
- Expectations after surgery
- Postoperative behaviour
- Self-image
- Other people
- Coping
- Hopes

12.4 Conclusions

There are many valuable themes identified through the course of these postoperative interviews and repertory grids. More detailed information is available in the full analysis in Appendix VII. These themes will be useful in the development of the treatment-planning tool and also as background to the third group of interviews.

CHAPTER 13

MAIN STUDY

GROUP 3

13.1 Introduction

Group 1 (Chapter 11) clearly outlined the varied experiences of women with UI. This confirmed the need for further work in this area and generated themes for future development of a treatment-planning tool. Group 2 (Chapter 12) focused on surgical management of SUI. As these accounts are all retrospective and from a group of women with ongoing problems there is no information on how they were preoperatively, apart from their own recollection, which could be influenced by subsequent events. Group 2 provided valuable information and themes on UI and surgical management specifically.

In this chapter a group of women (Group 3) were studied twice – before and after surgery for SUI. This allowed prospective information gathering on each woman's views and expectations of her treatment, without the influence of her subsequent outcome. Many of the women in Groups 1 and 2 were not satisfied, given that they

were still attending the continence services. This contrasts with Group 3 as this will contain women who are cured/satisfied and will be discharged from the continence services in due course.

13.2 Design

A research protocol (Appendix IV) was designed to capture cure, satisfaction and dissatisfaction by both subjective and objective outcome measures. The subjects were classified as cured or not cured and those that were cured but not satisfied were the main focus of the analysis. Each stage of the research protocol is outlined in Table 13.1.

Table 13.1 Research protocol for study group 3

Research measure	Time of application	Purpose
Preoperative repertory grid 1	Between the decision for surgery and the operation	An opaque measure of women's expectations of surgery
Preoperative repertory grid 2	Between the decision for surgery and the operation	An opaque measure of terms in which women enjoy/dislike things
Situations affected by incontinence list and pad use	Between the decision for surgery and the	A subjective direct assessment of the subjects' preferred environments. To see their reasons given for wearing

	operation	pads
Kings Health Questionnaire	Between the decision for surgery and the operation	An accepted QoL measure to compare scores to postoperative score as an outcome measure
Preoperative qualitative interview	Between the decision for surgery and the operation	To explore the subject's experience of UI and their treatment to date. To explore their expectations of their surgery. To compile a problem list to pose postoperatively to see which issues have not been addressed by their treatment
Preoperative urodynamics	Before the decision for surgery	To compare with postoperative urodynamics as an objective measure of cure
Assessment of subjective success of surgery for stress incontinence visual analogue scales (VAS)	At least six weeks postoperatively	A subjective quantitative outcome measure
Postoperative repertory grid 1	At least six weeks postoperatively	To compare their outcome with how they think they expected to be postoperatively
Postoperative	At least six weeks	To see in what terms they choose

repertory grid 2	postoperatively	preferences postoperatively
Postoperative situations affected by incontinence list and pad use	At least six weeks postoperatively	To see if their preferred environments had changed. To see if they still wear pads and if so, why.
Postoperative qualitative interview	At least six weeks postoperatively	To explore their experience of surgery and life after surgery. To identify any areas of dissatisfaction with their treatment.
Postoperative urodynamics	At least six weeks postoperatively	An objective measure of cure

13.3 Subjects

These women were identified through the course of urogynaecology and urodynamics clinics and from the surgical waiting list. The only inclusion criterion was that the decision had been made that they were due to undergo surgical treatment for SUI. They may have had surgery in the past or other medical and/or conservative treatments and these were not reasons for exclusion. A patient can change her mind about proceeding with surgery at any time until the anaesthetic starts and there is no guarantee at the point of recruitment that each woman will definitely go ahead with the surgery or indeed that she will attend for follow-up.

In total 42 women were invited to take part by letter or in person. Twenty-two women were successfully recruited. Several women had a preoperative research interview

but were excluded from the results for the reasons in the following table. In total 14 complete case studies were completed.

Table 13.2 Excluded subjects (Group 3)

Subject	Reason for exclusion
I	Patients did not go through with the operation but opted for physiotherapy treatment
II	Operation was postponed. Reason not known
III	Operation was postponed. Reason not known
IV	Preoperative interview was stopped during the first repertory grid at the patients choice
V	Did not attend postoperative research assessment
VI	Surgery was cancelled because of detrusor activity
VII	Operation was not performed within the timescale of the study
VIII	Operation was postponed because of a flu-like illness

As with Groups 1 and 2, the study is concerned with each woman's experience of her condition and her management and therefore demographic information and biodetails were not collected.

13.4 Methods

Preoperative repertory grid 1

This was designed to be an opaque measure of people's expectations and hopes of surgery and how they relate to various time periods in their lives. This was developed following on from the repertory grids used in Groups 1 and 2 and is shown in Figure 13.1. Five elements are supplied and the subject chooses the sixth. Comparing in what way two of the elements are similar and a third different forms the bipolar constructs.

Figure 13.1 Blank repertory grid 1 (Study group 3)

Elements→ Bipolar constructs	Me before the bladder problems started	Me when my incontinence was at its worst	How I expect to be after surgery	How I hope to be after surgery	Me now	*Element chosen by subject. Something I would like to do that I can not do now because of the incontinence*
Bipolar construct formed by comparing and contrasting elements	O		O		O	

marked 'O'						
	O	O	O			
		O		O		O
			O		O	O
	O			O		O
		O		O	O	

Preoperative repertory grid 2

The elements are selected by the subject in response to the statements 'tell me three things you really enjoy or like' and 'tell me three things you dislike or hate'. Comparing in what way two elements are similar and the third different form the bipolar constructs. This is illustrated in Figure 13.2.

Figure 13.2 Blank repertory grid 2 (study group 3)

Elements→ Bipolar constructs						
Bipolar construct formed by comparing and contrasting elements marked 'O'	O		O		O	
	O	O	O			
		O		O		O
			O		O	O
	O			O		O
		O		O	O	

Situations affected by incontinence list and pad use

This is a self-completing list asking 'please list five situations where your incontinence causes you the most difficulties' and 'please list five situations where your incontinence is less of a problem to you'. Additional written questions are 'Do you wear pads or any extra protection?', 'if yes, what sort of pads do you use?', 'how many a day do you use?' and 'why do you wear them?' The purpose of this enquiry was to establish directly what the subject finds most difficult and see if this changes postoperatively. The reason for wearing pads was examined as this is often felt to reflect leakage but may reflect other concerns such as hygiene or odour. It was also an intention to establish if women stop wearing pads if they are dry postoperatively. In other words do they adapt to being continent in this one respect?

Kings Health Questionnaire

The KHQ is a validated recognised QoL tool specific to UI. It is used in this study as a quantitative measure of success. There are a series of questions, which are self-completing. The results are displayed as scores for various domains. The score for each domain is calculated by set formulae as outlined the Appendix V.

Preoperative qualitative interview

This was a free flowing time unlimited interview performed in the same way as Group 2. The opening question was 'tell me about your bladder problems from the start'. The interviewer prompted and questioned as little as possible to keep the interview going until the topic was exhausted. There was enquiry into what the subject expected following surgery if this was not already covered. The interview was written

and typed up after the interview concluded, as in Groups 1 and 2. This group of interviews was not thematically analysed. The complex topics surrounding UI were fully explored in Groups 1 and 2 to saturation and this group of interviews was not designed for that purpose. The purpose of this group of interviews was to look at each case in turn in relation to their end point of satisfaction or cure. A meaningful interpretation of their interview was therefore made in the light of their ultimate outcome and presented in case studies for those women who had some dissatisfaction despite successful operations.

Preoperative urodynamics

In this study urodynamics was performed preoperatively and postoperatively as an objective measure of cure. Preoperative urodynamics are performed routinely for every patient before SUI surgery. The clinical purpose is to confirm the diagnosis of SUI, more specifically USI and if there is significant DO to address this. Provoked DO can masquerade as SUI and this must be excluded, as SUI surgery is not appropriate if provoked DO is the diagnosis and USI is not demonstrated. Additionally if suboptimal voiding is detected then this helps in counselling women preoperatively that they may be at increased risk of needing to perform ISC and consideration given to teaching them this skill before they have their surgery.

Urodynamics is undertaken by recognised dual channel subtracted cystometry within the urogynaecology unit in BWH. The procedure involves measuring intravesical pressure by placing a fluid filled catheter into the bladder and measuring intraabdominal pressure by placing a second fluid filled catheter into the vagina or

rectum. The bladder is filled with fluid and the pressures are recorded and displayed on a computer screen in real time. These urodynamic traces can be printed out at the end of the test for future reference or if a second opinion is required. The pressures are displayed according to the passage of time and volume of fluid in the bladder. A number of measures and observations can be made. For the purposes of this study the information extracted from the results filed in the notes were: the presence of stress incontinence, the presence of DO on filling, the presence of provoked DO, evidence of voiding dysfunction and any additional comments. Sometimes there were difficulties with interpretation and these cases were usually discussed at the multidisciplinary meeting and a consenses made. Some women had videourodynamics or ambulatory urodynamics and these were taken into account also.

Assessment of subjective success of surgery for stress incontinence visual analogue scale (VAS)

This is a quantitative subjective outcome measure. It is self-completing and allows the subject to quantify five aspects of their outcome on a scale. The VAS is a 10cm horizontal ruled line. The left end is marked 0 and the right end is marked 10. For each scale 0 and 10 are defined. The subject is asked to make a mark on the line, which best represents their answer. The line is measured after the interview and recorded in centimetres from the left i.e. the distance from 0. It is expressed to two decimal places. The VAS questions are: How successful do you feel your operation has been? (0= not successful, 10= completely successful), How satisfied you are with the outcome of your operation? (0= not satisfied at all, 10= completely satisfied), How

happy you feel at the moment? (0= very unhappy, 10= very happy), How relaxed do you feel at the moment? (0= very relaxed, 10= very tense), How much urinary leakage you suffer now? (0= leak all the time, 10= never leak).

Postoperative repertory grid 1

This repertory grid (Figure 13.3) was adapted from the preoperative grid to take account of the subject having now had continence surgery.

Figure 13.3 Postoperative grid 1 (study group 3)

Elements→ Bipolar constructs	Me before the bladder problems started	Me when my incontinence was at its worst	How I expected to be after surgery	How I hoped to be after surgery	Me now, after I have had the surgery	*Element chosen by subject. Something that I can do now that I could not do before the surgery*
Bipolar construct formed by comparing and contrasting	O		O		O	

elements marked 'O'						
	O	O	O			
		O		O		O
			O		O	O
	O			O		O
		O		O	O	

Postoperative repertory grid 2

This was exactly the same as the preoperative repertory grid 2.

Postoperative situations affected by incontinence list and pad use

This was the same as the preoperative situations affected by incontinence list and pad use questions apart from the tense was changed to account for them already having had surgery i.e. 'Please list five situations where your incontinence (causes/) caused you the most difficulties' and 'please list five situations where your incontinence was (is) less of a problem to you.'

The purpose was to see what had changed in relation to this. The problem was that some subjects were cured and situations were not a problem and they answered as for before their operation. Some mixed problems before and after surgery. This measure was not therefore particularly useful as a postoperative comparitor. The pad use question was, contrastingly, very useful to explore reasons why women wear

pads postoperatively, particularly if they are dry. This is discussed in each case study where relevant.

Postoperative qualitative interview

This was used to explore each woman's experience of surgery and life since their operation. A list was compiled of things mentioned in their preoperative interview and they were asked about each of these things after their free flowing interview. This was to assess if they had achieved all they had hoped for preoperatively and identify those things that were not addressed by surgery.

Additional questions were then asked

- What is the best thing about your operation?
- What is the worst thing?
- Are you glad you had your operation or do you regret it?
- If a friend told you that she was going to have this operation what would you say to her?

These questions were the final opportunity for the subject to express overall how they felt about their surgery, and another subjective reflection of their satisfaction with the whole process.

Postoperative urodynamics

This was performed as an objective measure of cure. The process was the same as preoperative urodynamcis. The only difference being that postoperative urodynamics are not a usual part of clinical care and was only conducted for the purpose of this

study. Two of the 14 cases studied declined urodynamics but were not excluded from the study as they had all other measures performed and still yielded useful information.

Analysis

Each case study was looked at in turn to determine whether they were objectively cured on urodynamics. Their VAS was looked at for how much they leak postoperatively as a subjective measure of cure. Those women who do not report a leak or who do not have USI postoperatively are the focus of the analysis. Their other measures are studied to determine their level of satisfaction and those with a satisfaction less than expected by their level of cure are the cases to be investigated for causes of dissatisfaction. Their repertory grids, qualitative interviews, pad usage before and after surgery are scrutinised in turn to build up a picture of their issues.

13.5 Results

The full results for each of the 14 case studies are summarised in Appendix XII. This is the only group where the women were all preoperative at their first interview. This allowed collection of their expectations for surgery prospectively rather than retrospectively (as was the case in Group 2). Their expectations are outlined below. Following this there is an analysis of their outcome.

Expectations

The group of patients who were interviewed pre-operatively were asked specifically what they expected of SUI surgery. Their repertory grids also had elements about

how they expected and hoped to be after surgery compared to other time periods. The expectations from these case studies are explored below.

- Case study 1 expects to be not awful, feel lovely, not uptight and able to walk and shop with no difficulties. She was aware that there are two operations and she felt that the one she is going to have was not as bad as the other one but she heard a lot of good reports. She is expecting to do a lot of things after the operation. She said she is not ill but she feels depressed and stressed with it. She said she is leaving it to the Gods to do the trick and make life a lot easier.
- Case study 2 would like to be able to have a good laugh. She expects not to be leaking, worried, embarrassed or made fun of. She is expecting not to leak and not to have to wear pads all the time. She is actually expecting that her worry and embarrassment will be even better than before the bladder problems started. After surgery she would like to laugh, go on a fair ride, do an exercise class and just know she was not going to leak. She thinks if she is not leaking her family will not make fun of her.
- Case study 3 expects to be able to laugh, run, not leak, not wear pads or think about the bladder all the time. She is hoping she will be able to do almost anything she wants. She wants not to wet herself if she has an asthma attack. She worried about the epidural and doesn't know why. Her friend had a TVT and can't sit down to have a wee. Her friend says that otherwise it has given back her life and she is pleased she can now wear what she wants, trousers or a skirt and does not have to worry about leakage. She understands she

may need a suprapubic catheter or ISC because there may be voiding difficulties. She hopes to be dry and will not wear pads anymore.

- Case study 4 expects to be very similar to how she was before she had any bladder problems. She expects the TVT to work and wants to have no leaking, no SUI, not to be wearing pads and to feel normal and free. She has grown used to fitting her life around the bladder and wearing pads and cannot imagine it being different. While she has got used to it, she would like it not to be there. She knows if the tape is too tight she may not be able to pass urine and if it is too loose it may not work. She can see the sense in not having surgery but thinks it is not major surgery. She is torn between getting it over with and having the patience to wait.
- Case study 5 expects to be physically active, not wearing protection or leaking, not feeling left out, feeling younger and not embarrassed. She would like to play badminton. Straight after surgery she assumes it is going to be pretty grotty. She thinks the hardest thing will be sitting still and getting better but she realises that she has to do that and is a bit anxious. She says she has managed it for years and now she is going to interfere with her body. She is concerned that she is not going to do well. She supposes it is in the back of everyone's mind. She has done all the preparation and will do what she is told. She imagines she is going to have a couple of months off. She is not sure how she will be once convalescence is over she is hoping she will be able to do more adventurous things. After surgery she would like to drink copiously and hold it.

- Case study 6 would like to be able to run and jog. She expects not to be having bladder problems, be able to run, feel cured, normal and excellent. She is having an operation because she thinks they tried everything else they possibly could and this is the final stage. She was told it might not be 100 percent and she has read up what the surgeon said on the internet. She thinks she has more confidence in him and his work than he has. She is expecting with his operation and her doing everything that she is told she will recover quickly and stop the leakage. She feels her Pilates will help, as her muscles are very firm. She is trying to get herself as fit as possible before the operation so she recovers afterwards. She thinks her surgeon is brilliant, very professional and trusts him. She feels he will do all he can, as she will to make the operation a success.
- Case study 7 expects to have no problems, not be embarrassed socially, able to run, not feel cautious, not wetting herself and not be wearing pads. She has worn pads for so long she says she will be self-conscious. She worries that surgery is going to be a temporary thing, rather than permanent, because she had it before. She dreads going through all this if it is not going to be a positive result.
- Case study 8 expects to be able to sneeze without leaking, not feel embarrassed, to be sociable, able to dance, feel confident and not be conscious of the bladder at work. She does not expect to be as good as she was before the bladder problems started in these respects. She is having a colposuspension and thinks, why is she putting herself through all that when she is not ill? She spoke with colleagues who have put it in perspective that

her QoL will be better, if it works. She cannot imagine not leaking; it is a way of life. She wants to know if it is worth the end result because she is not ill and is young. The thought of not leaking is bliss to her. She wants to be able to laugh at work without crossing her legs. She does not feel physically unwell and to her an operation equals illness and she is not ill but can see the benefit of having it. If it does work it could be the best thing that ever happened to her. She would never have an operation for the sake of it. She cannot understand people having cosmetic surgery unless their ears stick out and it is affecting them. She just cannot comprehend that she is going to be jumping, running, cracking jokes, standing there. After surgery she does not have clear expectations because she heard her friend's mum had it done years ago and it was the best thing she ever did. Her best scenario is she will never leak again for the rest of her life but she does not know. She says she is not a medical person so she does not know. The reason she went for the colposuspension was because the long-term effect of the TVT is not really known and if she is going to have it done she only wants one thing done. She knows she could have the TVT and if it does not work have a colposuspension. She knows two people with TVT, one who thinks it was the best thing and one who thinks it was a waste of time. She says if she comes out okay and recovers it will change her life dramatically. She was worried because of the unstable bladder. She did feel a bit better because her surgeon felt that the colposuspension might help her small prolapse where the TVT would not. She says the best scenario is if she is free forever or at least until 70. She knows there are risks and she might have voiding difficulties. She says she is not

stupid and is prepared to take the risks. She is not going in with her eyes closed. She is a bit worried, as people have given her different advice. She is going away for her 40th six weeks after surgery. Mr_____ (urogynae) says it is fine, others say she is at risk of deep vein thrombosis and she is worried. Her GP said two weeks off work. Mr____ (urogynae) said six weeks and the nurse said 12. She will be driving straight after as well. She knows you are not really supposed to but she would have difficulty not driving for six weeks. She is determined to go on the holiday and says she will be great, laughing, sneezing, coughing and dancing the night away. It will be a milestone, the best birthday present.

- Case study 9 would like to be able to run. She expects to be able to do exercise, be carefree, have no leakage, and have no fear about surgery and no fear of smell. She does not expect to be as good as she was before she had bladder problems. She hopes this operation can make things a lot better. She will just be glad the surgery is here. She is not expecting perfection, just for it to be better than it is now. She is trying not to expect great things because she does not want to be disappointed. If it is better than it is now and surgery stops the problem that will be perfect. If she were able to live her life like she used to, even if it is just better, that would be great too.
- Case study 10 would like to be able to go rambling. She expects for improvements in relation to disability, normality, happiness and being watertight and the expectations for these elements are identical to before the bladder problems started. After the operation she says she has high hopes maybe not a complete cure. She expects an 80-90% cure from the leaflet. She

wants to be running for buses and if her husband gets better have longer walks and touring holidays. It will not affect her singing because she is standing still anyway.

- Case study 11 would like to be able to laugh and cough without leaking. She expects to be similar to how she was before she had bladder problems. She expects to have a proper lifestyle, a normal life, not to be wearing pads all the time, be able to cough, laugh and sneeze and to feel very nice being dry, to have what she is hoping for and to be happy. She can't wait to have it done and she hopes that it is successful and feels desperate. After the operation she thinks things will be wonderful. It would be good to sit in a room and have a good laugh and know she will not be wet. She spoke with a patient who had a colposuspension and is really happy. She says her husband will breath a sigh of relief if this works. She will feel happy and relieved. She is hoping that this is the last surgery she has to have.
- Case study 12 expects to be as active as she wants, not be embarrassed, not have leakage, be able to do what she wants, be able to walk as long as she wants and not be conscious of her bladder control. She does not expect to be as good as before the bladder problems started. She was thinking it was just an operation, now she is thinking more, about the short term, family commitments, work etc. She wonders how much she will be able to do soon after and not ruining whatever work has been done. Will she be able to drive, walk the children to school and work? She is hoping it is going to be effective in the long term. She is hoping she won't have to wear liners anymore and be able to go for a walk with the family without wondering how damp she is going

to be at the end of it. She is wondering whether urge incontinence might become an issue. If he does a repair, she is hoping that will make her feel more comfortable. It would be nice if her and her husband got more sensation when they have intercourse and that she might be able to keep a tampon in which is a problem. She can but it just tends to fall out sooner than it used to. She said she does not have too many expectations. She then started asking questions about the success rates of TVT in her interview and returning to normal activities.

- Case study 13 would like to be able to go jogging. She hopes to be the same as before the bladder problems started but does not expect this in relation to her ability to play with her children, exercise and jog. She does expect to be able to be normal sexually; able to cough without leaking, and able to run for the bus as well as before she had bladder problems. She decided to go for surgery for her, to get it done and get back on her feet, back to normal activity. She is hoping the surgery is going to be a lot better than when she was sterilized because the morphine did not agree with her and she kept being sick and fainted. After surgery she will be able to think about going out a lot more without having to worry about protection, clean underwear, clean towels, clean trousers and go out with a lighter bag.
- Case study 14 would like to be able to play with her children without thinking about running and jumping. She expects not to be thinking about precautions such as spare knickers and going home and she hopes and expects to be as good as before the bladder problems started in this respect. She also expects to not have to weigh up doing physical activities against not, not worry about

activities with the children, be physically comfortable, not be annoyed and be able to do aerobics. After the operation she hopes that she will be better. She says that she is a bit of a cynic and worries that it won't be better and her worst fear is it will actually be worse but she is trying to be optimistic. She says she might be one of the 90%. To be able to do aerobics would be fantastic and going for a jog and not worrying when she has a cough or playing with the kids. She hopes to be more adventurous in general and more spontaneous.

Outcome

The main purpose of Group 3 was to identify those subjects who were cured but dissatisfied. The measures in Table 13.3 were used as indicators to identify the relevant case studies.

Table 13.3 Outcome measures (Group 3)

Case study	USI on urodynamics postoperatively	Leakage score on VAS (10=no leak)	Pad use postoperatively	Success score on VAS (10= complete success)	Satisfaction score on VAS (10= completely satisfied)	Summary
1	No	10	No	9.95	10	Cured and satisfied
2	No	8	No	8.8	9.95	Fairly dry and satisfied
3	Very slight	7.85	No	8.4	9.75	Some leakage but satisfied
4	Very slight	3	Yes (for leakage	3.6	3.7	Very slight leakage but very poor

			)			outcome on self reported measures
5	No	9.95	Yes (for reassurance and habit)	8.55	9	Dry and satisfied but wearing pads for psychological reasons
6	No	7.4	Yes (for leakage)	7.1	5.6	Still leaks and not satisfied but no USI
7	No	9.1	No	5.9	5.5	Very little leakage and no USI but not satisfied
8	No	8.3	No	7.6	8.4	Some leakage equivalent satisfaction
9	No	8.7	No	8.5	8.5	Some leakage but not USI
10	No	10	No	10	10	Cured
11	No	4.9	No	9.9	9.6	Moderate leakage reported, no USI high satisfaction
12	No	9.4	No	10	10	Near cure completely satisfied

13	declined	9.3	Sometimes (if going out and has a cough)	9.9	9.8	Near cure very satisfied
14	declined	10	No	9.9	7.4	Success but not complete satisfaction

Those women who are cured but remain dissatisfied are the focus of this investigation. Table 13.3 illustrates the difficulties in defining cure. The shaded cases (4, 6, 7 and 14) are those with the most discrepancy and worthy of detailed study. These case studies have been distilled down to establish causes of dissatisfaction. Their reasons for dissatisfaction are ongoing leakage even though USI was much reduced (case studies 4 and 6). There is also worry because bladder sensation appears to be reduced even though this has helped the nocturia and is not a problem in itself (case study 4). Some suffer symptoms of OAB (frequency, urgency) even with no SUI but have provoked DO or OAB (case studies 6 and 7).

One woman says that the only benefit of her SUI surgery is that she does not leak (case study 7). She no longer leaks, or needs pads and her backache has gone. Traditionally this would be a 100% cure but yet she scores her success and satisfaction with treatment as only around 50% (5 out of 10 on the VAS). She still

gets urgency, fluid restricts, toilet maps, preventatively micturates and has actually started carrying wipes to clean the toilet seat even though she did not do this before her operation. Most of her problems postoperatively appear behavioural except urgency (case study 7).

Needing a catheter and/or needing to do ISC appear to impair some women's satisfaction even if SUI is cured (case studies 7 and 14). Some women feel anxiety related to UTIs or needing ISC (case study 14).

Even looking at the other case studies in detail there are factors of ongoing dissatisfaction, irritation and concern after treatment. Case study 1 still asks people if they can smell her. They say they could not even smell her before her operation. She was satisfied and cured but this concern persists. Case study 5 is still conscious of where the toilets are and concerned about the bladder. It causes her enough concern that she would be reluctant to sit on someone's pale suite even though she scores leakage as 9.95 (where 10 is 'never leaks') and postoperative urodynamics were normal.

Some people wish to be able to do things once their UI is cured that they cannot do anyway for other reasons. For example case study 3 wanted to be able to run after her SUI operation but when asked about this postoperatively she said that she would not really tend to run because of her asthma. Similarly her nocturia is not improved. She admits that she does not sleep well and this may be why she is getting up and going to the toilet. Her operation may have cured her UI but not her insomnia.

Some postoperative features prevent people achieving their full potential benefit of SUI surgery. Case study 4 was one such case. She does describe some SUI and a small amount of USI was demonstrated postoperatively. She is understandably concerned about this but she also has other less predictable issues causing her distress. Her nocturia is actually much better but she is concerned in case this means that her bladder sensation is abnormal. It is interesting that although she is leaking, wearing pads, and worried about the bladder she is still pleased she has the operation because she tried to improve her situation.

It can be difficult to change habits postoperatively, even if they were felt to be undesirable things to be doing. Case study 5, for example, is finding it difficult not to wear a panty liner even though she does not leak. She thinks she will try to do without it at home to start with before going out without a pad. Similarly she wanted to be able to wear a skirt and not to have to wear dark colours. At the time of her postoperative interview she had not changed her clothing habits even though she was not leaking. She was, however, doing ISC and this might have been part of the reason for this. Case study 14 has got used to crossing her legs before coughing and braces herself when the dog pulls on the lead even though these things do not make her leak anymore. She thinks it will be hard to change these things and she will need to make a conscious effort to be able to change her behaviour.

Urge seems to be a problem for some women after USI operations and this may limit their satisfaction with their operation. Case study 6 had OAB symptoms but no DO on

pre-operative urodynamic studies. Postoperatively she feels she has a little more control but her ongoing OAB symptoms have prevented improvements in anxiety related to fear of big leaks with a secondary impact on her world and family life. She has not been able to improve her self-control. She is still pleased she had the operation done even though she did not score her satisfaction well on the VAS (scoring 5.6 where 0 is not satisfied at all and 10 is completely satisfied). Provoked DO was demonstrated on urodynamic studies postoperatively leading to commencement of anticholinergic medication. Similarly case study 7 no longer wears pads and says that she does not leak and that is the only benefit. On the surface, continence would be seen as complete success. She suffers frequency, urgency, embarrassment at doing ISC and having a catheter at home, fluid restriction, toilet mapping, poor flow, self-consciousness and preventative micturition. She carries spare underwear and has only started carrying wipes since the operation to clean the toilet seat. On deeper questioning she had actually had two episodes of urgency incontinence and her postoperative urodynamics did show slight provoked DO without leakage. She is still hoping that things will improve. Case study 8 has occasional leakage for no reason but is thrilled with her operation. Her main issue is the length of time of recovery and the discomfort and tiredness. She did not feel properly prepared for the colposuspension even though she remembers the doctor saying it was a big operation. She admits to toilet mapping, and occasional leakage but she does not wear protection as she sees it as very minor. She feels she has much more freedom and less anxiety. She thinks people should be better prepared but also feels it is not desirable to frighten people. She suggests telling them it is a long recovery period (for colposuspension). Case study 11 is very satisfied with her

outcome and feels that the operation was successful. She scores poorly for leakage, happiness and tense, scoring these around 5 out of 10. Her main problems postoperatively have been urgency although this did not show up on her urodynamics. Case study 12 has mild urgency problems but they do not seem to impact on her and did not show up on her postoperative urodynamic studies.

Underlying mood may not be changed by changes in UI. Case study 11 feels her depression is better since her SUI operation but it is still there. She said her depression was 10 out of 10 but postoperatively it is 4 out of 10. She wanted to feel wonderful postoperatively but she only feels good. It is debateable whether she would ever have felt wonderful with her underlying depression unless this was addressed directly. She is on antidepressant medication postoperatively which may have accounted for some of the improvement in mood. She does have ongoing urge and this may also have restricted her benefits, unrelated to mood. It is challenging to separate these effects out in this single case study but it does illustrate nicely the interplay of different conditions on one's experience of disease and life.

People have other concerns that may prevent them from achieving their full benefit of successful UI treatment. Case 11 worries about being overweight as well as having underlying depression. She also has joint pain and arthritis. Case study 8 has noticed she has put on weight since the operation.

Voiding dysfunction, requiring catheterisation, was experienced by several of the case studies. Some seemed to accept it and it did not appear to affect their overall

outcome. Others seemed to feel it was a disappointment and limited how positive they were about the operation even if they were dry and the ISC was temporary. Some women with ISC also had urinary tract infections, which appeared to impair their experience further. These complications cause anxiety for some women even if, like case study 14, they are able to be more spontaneous, adventurous, jog and do not leak. These examples clearly illustrate that women whose UI is clinically cured continue to experience psychological problems.

13.6 Conclusions

Even on a small sample, in quantitative terms, it is possible to identify women with suboptimal outcome and where satisfaction does not match success or cure.

CHAPTER 14

COMPARISON OF DATA

14.1 Introduction

Although this study is mainly qualitative and the main focus is on themes, it is possible to apply statistical representations and analysis to much of the data. The following sections display examples of this for the purpose of representing some aspects of the data in a succinct way.

14.2 Venn diagram of themes

Aim

To assess whether a current accepted measure of quality of life in women with UI, the Kings health questionnaire (KHQ), really captures the full experience of UI demonstrated by other measures.

Method

The global themes were identified from the literature review of women's experiences of UI and major themes identified from the patient focus group. These were displayed on a Venn diagram, showing which themes are common to these two sources and the domains of the KHQ.

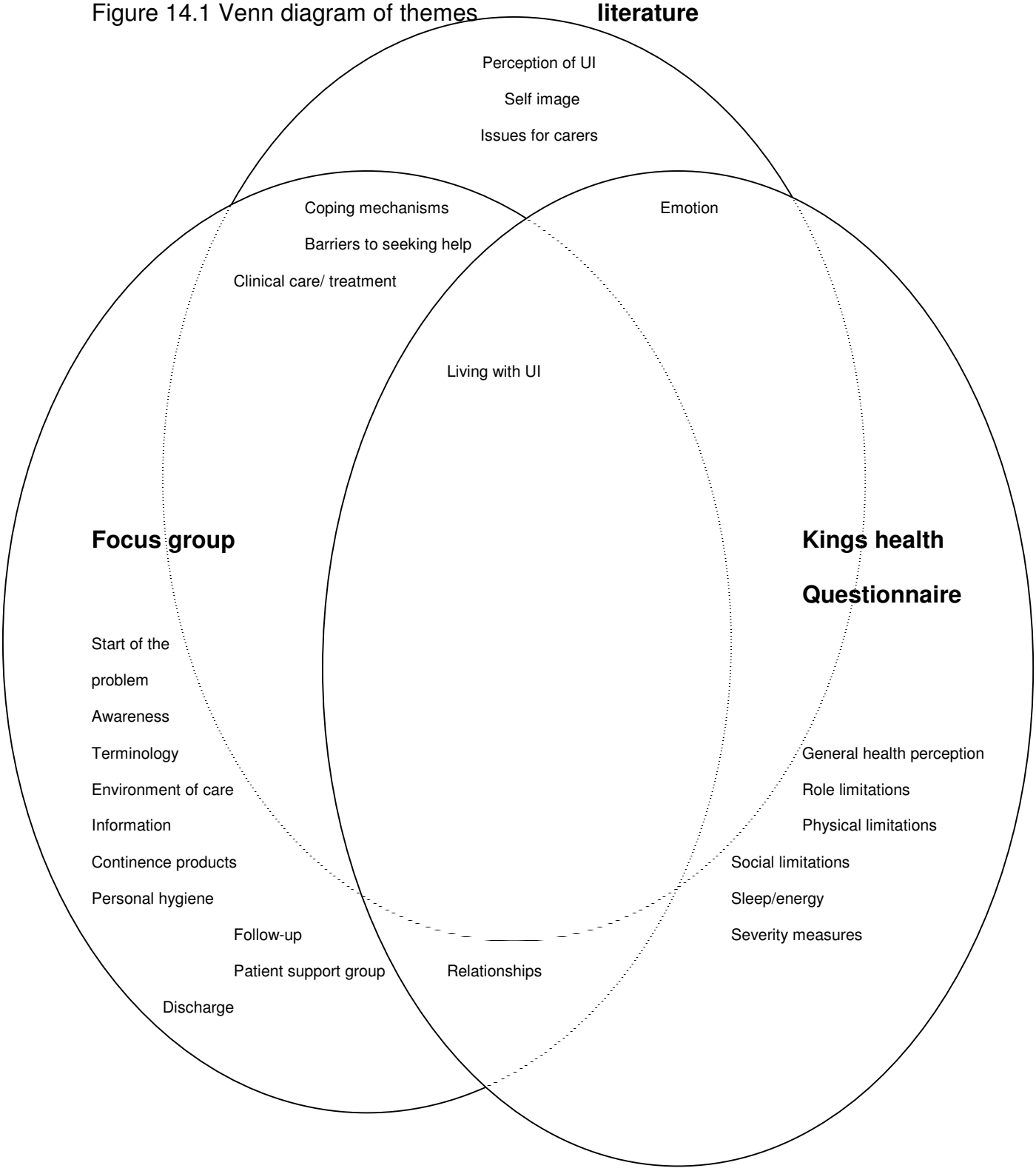
Results

The results are displayed in the Venn diagram following.

Conclusions

There is very little overlap in the three sources regarding major themes of UI. The KHQ may not be sufficient to capture the full range of patient experiences of UI. This supports the need for a better way to capture information from patients as part of individualised treatment-planning.

Figure 14.1 Venn diagram of themes **literature**



14.3 Venn diagrams of the repertory grid constructs for the three patient groups

Aim

To compare the three patient groups by examining the global themes from their repertory grids.

Method

To extract the global themes from the repertory groups and plot them on a Venn diagram.

Result

The result is displayed on the Venn diagram.

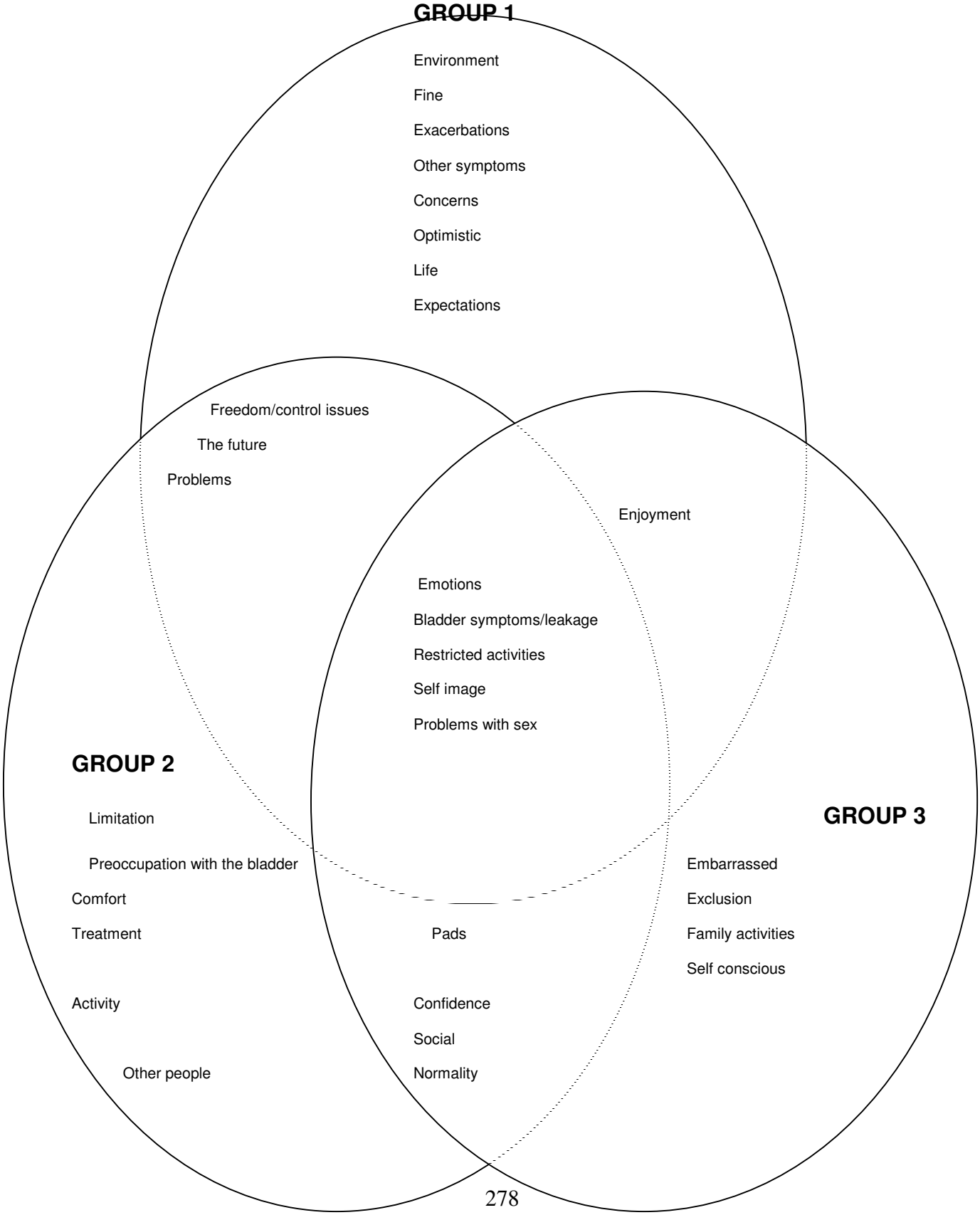
Conclusion

There is a certain amount of overlap between the groups themes.

Limitation

The global themes are arrived at independently for each group. There may be more in common than initially appears if the organising themes and basic themes were revisited but this is not amenable to this analysis. The diagram is useful to see the spread of themes throughout the entire studied sample at a glance.

Figure 14.2 Venn diagrams of the repertory grid constructs for the three patient groups



14.4 Related ‘t’ test for the Kings Health Questionnaire (Group 3)

Aim

To measure whether the total KHQ scores are significantly different after surgery compared to before surgery.

Method

A related ‘t’ test was performed as below:

PRE-OP KHQ scores

Case	General health perception	Incontinence impact	Role limitations	Physical limitations	Social limitations	Personal relationships	Emotions	Sleep/ energy	Severity measures	PRE-OP TOTAL	
1	0	100	100	83.33	100	0	100	33.33	100	616.66	
2	25	100	50	83.33	66.67	66.67	100	8	86.67	586.34	
3	25	100	66.67	66.67	33.33	50	22.22	66.67	86.67	517.23	
4	25	66.67	66.67	66.67	11.11	33.33	33.33	50	66.67	419.45	
5	100	66.67	50	83.33	44.44	N/A	44.44	16.67	40	501.24	*
6	0	66.67	83.33	50	55.56	0	11.11	33.33	66.67	366.67	
7	50	100	100	100	88.89	83.33	66.67	50	100	738.89	
8	25	100	66.67	66.67	44.44	0	88.88	16.67	93.33	501.66	
9	25	66.67	66.67	50	44.44	33.33	100	50	86.67	522.78	
10	25	66.67	66.67	83.33	66.67	33.33	44.44	33.33	53.33	472.77	
11	50	100	50	50	88.89	33.33	88.89	66.67	80	607.78	
12	0	100	33.33	50	44.44	55	55.56	66.67	80	485	
13	50	100	83.33	83.33	11.11	66.66	100	66.67	86.67	647.77	
14	25	100	33.33	66.67	44.44	0	33.33	33.33	33.33	369.43	
										7353.7	

* Has been multiplied by 9/8

POST-OP KHQ scores

Case	General health perception	Incontinence impact	Role limitations	Physical limitations	Social limitations	Personal relationships	Emotions	Sleep/ energy	Severity measures	POST-OP TOTAL	
1	0	0	0	0	0	0	0	66.67	0	66.67	
2	33.33	0	0	0	0	0	0	0	40	73.33	
3	25	33.33	16.67	0	0	0	11.11	66.67	26.67	179.45	
4	50	66.67	33.33	83.33	44.44	0	55.56	50	53.33	436.66	
5	0	33.33	0	33.33	11.1	N/A	22.22	16.67	33.33	168.73	*
6	25	66.67	33.33	33.33	11.11	0	22.22	33.33	60	284.99	
7	50	66.67	50	50	44.44	50	44.44	50	66.67	472.22	
8	50	33.33	16.67	0	0	0	44.44	50	20	214.44	
9	0	33.33	0	16.67	0	0	0	16.67	0	66.67	
10	25	0	0	0	0	0	0	33.33	6.67	65	
11	50	66.67	66.67	66.67	22.22	16.67	44.44	33.33	53.33	420	
12	0	0	0	0	0	0	11.11	16.67	13.33	41.11	
13	25	0	0	0	11.11	50	0	16.67	26.67	129.45	
14	25	66.67	16.67	0	11.11	0	22.22	50	6.67	198.34	
										2817.1	

* Has been multiplied by 9/8

Case	PRE-OP TOTAL	POST-OP TOTAL	d	d^2
1	616.66	66.67	549.99	302489
2	586.34	73.33	513.01	263179.3
3	517.23	179.45	337.78	114095.3
4	419.45	436.66	-17.21	296.1841
5	501.24	168.73	332.51	110562.9
6	366.67	284.99	81.68	6671.622
7	738.89	472.22	266.67	71112.89
8	501.66	214.44	287.22	82495.33
9	522.78	66.67	456.11	208036.3
10	472.77	65	407.77	166276.4
11	607.78	420	187.78	35261.33
12	485	41.11	443.89	197038.3
13	647.77	129.45	518.32	268655.6
14	369.43	198.34	171.09	29271.79
Sum	7353.67	2817.06	4536.61	1855442
Mean	525.26	201.22		
Count, N	14			

Result

t =	7.042	**P < 0.0005**

Conclusion

The changes in scores (improvements) of the KHQ from before surgery to after surgery are very significant when analysed by this test.

14.5 One-way ANOVA on visual analogue scales (Group 3)

Hypothesis

The hypothesis for this analysis is that women who have undergone SUI surgery show differences in outcome related to subjective success, satisfaction with the outcome of their operation, feeling happy, feeling relaxed and absence of leakage.

Method

The 1-way ANOVA is suitable for analysis of one group with three or more conditions. The results from these conditions are compared for differences between them. The data are of an interval/ratio level.

Design

The design for comparison of differences is a single study group of women who have undergone surgery for SUI. The conditions are self-completed VAS scores on:

- Subjective success of surgery
- Satisfaction with outcome
- Feeling happy
- Feeling relaxed
- Subjective assessment of dryness

This data was measured on a VAS from 0 to 10. All of the good or positive outcomes were at the 10 end of the scale except happy/unhappy, which was the other way around with 0 being very happy. For the purpose of this analysis each score was

subtracted from 10 to give a new score in keeping with the other VAS question's polarity. Each condition is therefore assigned a mark out of 10. This fulfils the requirements of a parametric test.

If the hypothesis is true there would be an expected significant difference in the 'between conditions variation'. The 'between subjects variation' can also be tested for significance.

Calculation summary

Calculation of the 1-way ANOVA:

Case study	Success	Satisfaction	Happy	Relaxed	Dry	Total for SS
1	9.95	10	10	10	10	49.95
2	8.8	9.95	9	7.9	8	43.65
3	8.4	9.75	9.6	7.6	7.85	43.20
4	3.6	3.7	1.65	4.9	3	16.85
5	8.55	9	9.3	7.25	9.95	44.05
6	7.1	5.6	5.4	9.25	7.4	34.75
7	5.9	5.5	7.55	9.5	9.1	37.55
8	7.6	8.4	8.1	8.2	8.3	40.60
9	8.5	8.5	10	10	8.7	45.70
10	10	10	10	10	10	50.00
11	9.9	9.6	4.5	5.3	4.9	34.20

12	10	10	7.7	8.5	9.4	45.60
13	9.9	9.8	9.5	5.3	9.3	43.80
14	9.9	7.4	7.35	6.55	10	41.20
Totals	118.10	117.20	109.65	110.25	115.90	Grand total 571.10

ΣTc^2 = sum of squared totals for each condition = 65294.445

ΣTs^2 = sum of each subjects performance squared = 24210.19

n = number of SS or sets of matches = 14

C = number of conditions = 5

N = total number of scores = n x C = 70

Σx = grand total = 571.10

$(\Sigma x)^2/N$ = a constant to be subtracted from all SS = 4659.360143

Σx^2 = the sum of each squared individual score = 4942.18

SS bet = $\Sigma Tc^2/n - (\Sigma x)2/N$ = 4.528786

SS subj = $\Sigma Ts^2/n - (\Sigma x)2/N$ = -2930.06

SS tot = $\Sigma x^2 - (\Sigma x)^2/N$ = 282.8199

SS error = SS tot – SS bet – SS subj = 3208.352

df bet = number of conditions – 1 = 4

df sub = number of SS – 1 = 13

df error = df tot – df bet – df subj = 52

df tot = N – 1 = 69

MS bet = SS bet/df bet = 1.1321965

MS subj = SS subj/df subj = -225.389

MS error = SS error/df error = 61.69908

F ratio for ‘between-condition’ variations = MS bet / MS error = 0.01835

F ratio for ‘between-subjects’ variation = MS subj / MS error = -3.65304

Source of variation in scores	Sum of squares (SS)	Degrees of freedom (df)	Mean squaring (MS)	F ratios
Variation in scores between conditions	4.528786	4	1.1321965	0.01835
Variation in scores between subjects	-2930.06	13	-225.389	-3.65304
Variation in scores due to random error	3208.352	52	61.69908	
Total	282.8199	69		

Results

Significance between conditions:

For a df of 4 and a df error of 52 the critical value is between 2.53 and 2.61.

The F ratio is 0.018 and therefore this is not significant at $p<0.05$. It is also not significant at $p<0.001$.

Significance between subjects:

For a df subj of 13 and a df error of 52 the critical value is 1.92 to 2.0. The F ratio of –3.65 is therefore significant at the $p<0.05$ through to $p<0.001$.

Conclusions

Using a one-way ANOVA for related subject samples on the data ($F=0.018$ $N=70$ $n=14$) it was found that the results were not significant at $p<0.05$ for a difference in VAS scores. There was, however, a significant difference between subjects ($F=-3.65$ $N=70$ $n=14$) at $p<0.05$ through to $p<0.001$. In other words the hypothesis that women who have had SUI surgery differ significantly on their VAS outcome measures is not true, but there is a significant variation between the women studied.

CHAPTER 15

COMBINED THEMATIC ANALYSIS

This Chapter was presented in part at the International Continence Society (ICS) in San Francisco in 2009 entitled 'Women's experiences of stress incontinence surgery'[9]. It has also formed the basis of several other presentations and publications[5;7;155;197].

15.1 Introduction

A great many themes surrounding women's experiences of UI and it's treatment have been identified by the networks shown in the preceding chapters from the literature (Chapter 8), the focus group (Chapter 9) and study groups 1 and 2 (Chapter 11 and Chapter 12). To interpret the thematic networks meaningfully requires the sources to be revisited and the themes explored. Section 15.2 represents the description and interpretation of the combined thematic networks for all of these sources. It is illustrated by examples throughout the analysis.

15.2 Findings

The analysis is presented in two sections - experience of UI and experience of treatment.

Experience of urinary incontinence

The global themes are:

- Start of the problem
- Cause of the problem
- Symptoms
- Living with incontinence
- Restrictions
- Control issues
- Relationships
- Other people
- Impact of the bladder
- The future
- Concerns
- Emotion
- Perception of the condition of UI
- Self-image

Start of the problem

The beginning of incontinence is rarely clear[27] and some people do not recall the start of the problem because it was a long time ago as they delayed seeking help. Often there is a reluctance to accept that they were incontinent with an unwillingness to discuss it, feeling embarrassed by their symptoms.

Cause of the problem

Women hold various beliefs about what caused their bladder problems including childbirth, epidurals, being overweight, emotion, infection, surgery and ageing. One woman theorised that because of her back problems she had lost height and the lack of space for her bladder was resulting in her bladder problems. There is recognition that bladder and bowel problems may be interconnected. One woman thought there was something pushing on her bladder. Another woman felt she did not use her brain enough and did not have a lot to take her mind off her bladder. One interviewee was worried there may be an underlying medical cause. Some women blame their own behaviour such as holding on too long before going to the toilet or drinking too much fluid. There is also a belief that it is a part of ageing to be accepted.

Symptoms

Many symptoms of OAB and SUI were described. SUI symptoms included leakage with activity, coughing, sneezing and laughing. Exercise causes leakage for many including star jumps, trampolining, dancing, running, jumping and aerobics. Daily activities like picking up children, lifting items in the supermarket, running for a bus or even walking slowly can result in leakage.

OAB symptoms included frequency, urgency and nocturia. Triggers include running water, putting a key in the door, walking uphill, getting off the bus, distraction, standing up at work and getting out of bed. There is also the unpredictability of not knowing when it will happen. One woman stated how her whole bladder empties. Toilet mapping was also described.

Wetness and leakage in general were described, as was the experience of wearing and changing wet pads. Other symptoms are leakage with sex, incomplete emptying, discomfort and UTIs. Sometimes there is discomfort when trying not to pass urine. One woman describes an ammonia type smell. Secondary effects included feeling uncomfortable at night and consequent tiredness.

Some subjects also feel they have symptoms arising from other conditions, equal to or worse than their bladder symptoms e.g. bowel problems, abdominal pain, leg pain and itching.

Living with incontinence

There can be an inevitability with no clear course[27]. Careful anticipation, mindfulness and lifestyle modifications become a way of life[27] with obsessive bladder emptying[25;27], toilet mapping[25;27], route planning[25;27], selecting safe outings and activities[27], avoiding dangerous movements[27], fluid restricting[25;27] and clothing restrictions[27]. The aim is to reduce the risk of leakage[25].

Practicalities include washing, changing and using absorbent products[25] particularly to allow people to go out of their homes. Marital problems occur as a result of poor bladder control during sex with planned trips to the toilet before and after sex[25]. For Muslim women UI interrupts prayer with resultant relationship problems and stress[25].

There can be a loss of independence with UI with the loss of physical capabilities[117] and an inability to maintain personal hygiene. Some sufferers are unable to continue

their spousal or parental role[117]. While some find life with UI isolating[27] there can be a benefit to sharing problems through talking[25]. Social life is affected with some feeling reclusive. Some have difficulty going out and find it easier in a familiar environment or with people who are already aware of the problem.

Life in general has been described as bad. Some people feel they are not as good as they used to be. UI has effects on self-image and confidence. Mobility problems make it difficult to get to the toilet on time. Another woman feels her life is a misery between her bladder, bowel and back problems. Faecal incontinence requiring pads is suffered by one of the participants. One woman worries as she gets pain related to not being able to pass water.

People do still enjoy activities that make them feel happy, relaxed and peaceful such as travelling, walking and gardening. Some activities are not enjoyable making people feel miserable and tense sometimes related to a preoccupation with toilets. Interestingly, UI often does not feature in repertory grids of disliked activities.

Restrictions

As well as a general restriction in freedom many people discuss wide ranging restrictions; lifting things, walking the dog, dancing in a nightclub, using the gym, laughing, jobs, housework, fluid intake, shopping, socialising, sex and travel. Specific restrictions included not being able to go out without pads and spare pants and having to plan to go out. It is perceived that there is an inability to lead a normal life.

One participant showered after the gym before work because of leakage, taking extra time. Avoiding exercise leads to resultant weight gain.

Restriction on time can make it difficult to sit through meetings and people can have difficulties making employment or committee commitments. One woman was a checkout operator and has to wear towels and go to the toilet often. Some women have difficulty travelling for work and several women have lost their jobs. Another woman, whose treatment was helping, was considering returning to work. One participant, who runs a playgroup, says she has bladder accidents when she runs around. One woman's boss would say 'are you coming?' while she is standing trying to get bladder control.

Travel restrictions and toilet mapping are common. Women may restrict fluids and keep stopping on their journey. People recount leaking on the floor of an airplane toilet, wetting the car seat or getting caught out on a bus. One woman described how she wet the bed sheets on her holiday, washed them and then dried them with a hair dryer. Some women describe needing to take extra clothes on holiday and having to carry spare knickers and clothes around. Clothing restrictions were mentioned. Some women only wear skirts in case they need to nip behind a bush or because it is easier to change. Conversely some women feel they cannot wear skirts, as wet patches are visible. Some won't wear trousers as they feel hot and sweaty or because of having to wear thick pads. Some women complained they could not wear nice underwear.

Unpredictable leakage means there is a preoccupation with thinking about the bladder and where the toilets are. One woman commented on the predictable nature of SUI but with urge you have no idea when it will happen.

One woman mentioned she felt restricted by her frequency. Another felt the restrictions hold her back, another reported that she does not have a life at all and she cannot do all the things she wants to. The bladder can seem to control lives and a reluctance to go out can result in lack of confidence.

Control issues/freedom

When women are not in control of the bladder then their freedom is restricted and life can become complicated. There can also be problems if a toilet is not available resulting in a wait.

Relationships

UI affects relationships and sometimes they change when women have more information and accept their diagnosis. Treatment helped one woman's marriage. There was a description of feeling shamed and embarrassed and sleeping in separate beds because of worry about leakage and odour. Coming to hospital helped one woman to discuss UI with her husband. Sex was restricted for many women with avoidance being common practice. Another says she can rarely have sex because she will leak. Another woman felt she shunned the whole sex act, being unsure whether to risk having the pad off or having to get up out of bed, take the pad off and wash. She said it was easier to pretend she is asleep or has a headache and says it

is like going to bed in a nappy. One woman described how she is frightened to get into a relationship and does not feel confident to go out and meet somebody.

Some women worry about odour and this puts them off sex. Some women feel bad for their partners. One woman said her husband is okay, but sometimes wants to make love. Sometimes she agrees to try but then she just cannot manage it. Another participant said she does not feel sexy when she is padded. Loss of spontaneity is described because of the need to preplan sex and have cleaning routines. One woman said there were problems with sex and her husband usually understood but that he wants to make love to his wife.

Other women feel they cannot keep up with their husbands and one said her husband gets irritated with her. One patient felt her husband had no patience, which caused arguments. He did help her by making a device out of a lemonade bottle to help her pass urine in the lay-by.

One woman comments that it probably affects the partners but she did not ask hers and they have been together for 45 years. She says he probably does not know whether to touch her or not. She felt it would be helpful to talk over things like that because she would not be comfortable talking to her husband about that.

Other people

Participants describe restrictions in their activities with other people and encounter difficulties socialising. One woman describes how her restrictions have a knock-on effect on her family life. People have difficulties such as playing football with their

children, keeping up with partners and fully participating with grandchildren. One woman describes how, when out with friends, she has to find a toilet before she can even order a drink. Some subjects avoid social invitations by making up excuses.

There can be problems staying in other people's houses in case of wetting the bed. One woman felt other people were looking at her because she was not able to take a drink on holiday. Some women feel it is very difficult to even go out of their house with one stating that she feels there is a psychological problem as soon as she goes out. One woman who does ISC will not do it when out in public and would prefer an indwelling catheter.

There can be a dependency on other people if not able to use public transport. There can be a reluctance to reveal how bothersome things are and some participants do not want to burden other people. Often there is secrecy surrounding bladder problems and a fear of discovery. Women often mentioned their partners and unwanted attention from various sources.

One woman said she tells colleagues she is going for a shower at work because of the heat rather than admitting to UI. One passes urine into a bowl at work and is worried that a cleaner will find her. She was also concerned that work colleagues noticed her frequency. Another woman was worried other people would be able to smell her. Many participants do not want anyone else to know and one woman had her operation when not working so as not to have to tell people. Some did not want to have to tell their insurance company what the operation was. Women comment on

their bladder problems being noticed by others. Another lady describes how she was witnessed getting caught out just before a meeting.

Participants sometimes compare themselves to elderly patients and express fear of old age. One participant works with incontinent patients and feels sympathetic towards them. People compare themselves with others especially their mothers. Support was also felt from staff.

The media influenced some participants with one women comparing herself to a woman on the television who was having an operation which she was told was not suitable for her. This made her doubt the medical decision again.

Some people receive unwanted attention. For example one woman's grandchildren and husband make a big thing of it. Participants felt that other people would not be able to understand unless they have the problem themselves.

Some people who had inpatient bladder retraining realised that other people were worse off than them. One woman made the suggestion putting everyone in a room so they are forced to talk to each other. Some people feel that there are other conditions that are worse e.g. a colostomy or recurrent pregnancy loss. Some people are aware of other patients' restrictions and make distinctions that they refuse to stay in because of it.

Impact of the bladder

Bladder symptoms have a great impact on many areas of participants' lives. In addition to limited physical activities, attendance at family events and even going out of the house at all can be a challenge. Leakage can occur during activities but there is also the interruption of having to go to the toilet.

One participant recalled childhood memories of her parents keeping a potty and a sponge in the car and of putting her hand up at school and not being allowed to go to the toilet. As an adult she remembers having to leave family funerals to find toilets and one occasion when she had to knock on a stranger's door to use the toilet.

Far-reaching areas are affected by the bladder, including hobbies, holidays and general QoL. One woman felt her problems affected her self, and her relationships and another woman felt that her life had been ruined.

The future

Sometimes there is optimism and hope looking ahead. There can be expectations of successful treatments or sometimes an unknown outcome; some hope for improvement and not needing pads. Some women accept some ongoing problems but an overall improvement. There was generalised fear expressed for the future, sometimes by comparison with elderly people.

One woman hopes to take long walks with trousers and trainers and not embarrass herself. She is concerned she will end up dirty, smelly and unclean. Another woman

does not see things changing in the future whilst a further participant wants to lead a healthy life and not deteriorate. She does not want to wear sanitary towels and incontinence pads for the rest of her life or to be thinking about going to the toilet all the time. Some women hope to get back to normal, have a good nights sleep and increase their clothing options and freedom by not toilet mapping.

One woman feels like her life is closing in, like there is not much time left. She feels older than she is and thinks about physical deterioration. In contrast, another woman expects to be fine in the future.

Concerns

Concerns include hygiene, pads, age, finance, body and normality. Several interviewees worry about smell and hygiene. Some were not even reassured when told they did not smell by their partner. One person worried that using public toilet paper could infect her prolapse. Another woman will not do ISC in public toilets. Some people feel that baths make them feel cleaner. Other women carry wipes.

Pads were mentioned in many interviews. One participant complained that the pads were bulky like a nappy. Embarrassment at buying pads was expressed and one woman coped by thinking that they were not necessarily for her. The cost of pads was an issue for several women. Toilet paper was used instead but found to be irritating. One woman said she would rather spend money on her family than continence products.

Many participants mention old women in their interviews. Several participants said they feel older than they are. One woman went on to explain how she thinks things are designed to deteriorate from the age of 40 and not much beyond 50 and she has reached that point.

Emotion

Negative emotions include regret, fear, anxiety, devastation, sadness, worry, shame, unhappiness, crabbiness, awfulness, isolation, self-consciousness, low self-confidence, embarrassment, humiliation, depression, frustration, disappointment, dread, feeling despondent, bad, upset, not good, tense, negative and uncomfortable. A sense of sadness and regret for losing freedom, spontaneity and QoL was expressed[27]. Some people live in dread that the incontinence might get worse[27]. Some women have low self esteem with expressions of shame[25;118], dirtiness[25], embarrassment[25;118], sinfulness[25] and self-blame[25]. Anxiety encompassed fear, mental stress, worry, fear of not being able to find a toilet quickly and fears for the future[25]. Some emotions relate to dependence on others[117] and feelings of isolation[160;161]. One woman was anxious about the cause of her problems. One woman described feeling frustrated when she leaks after getting showered and into clean clothes. Others are fed up or hate being wet. There is a feeling of frustration with time and money spent on the problem with getting cleaned up and buying things. Some patients cried during their interviews while others admitted to having cried. Other negative emotions included feeling fraught, and abused.

Some participants expressed self-pity as though the way the health system treated them made them a victim like they were being put through hoops or passed around. Some felt they were not being heard or were dismissed. Some felt their hopes were dashed when put off surgery in case it made their condition worse. Some women experienced doubt in the way they were managed. One woman said she felt horrible during video urodynamics. One felt awful at the way her consultant spoke to her.

Regret was experienced by a woman who had a hysterectomy, which she felt had caused her problems. One woman felt devastated because she felt she had limited treatment options. One of the participants expressed disappointment that life is not what she expected it to be. Another woman had a ten-year history of anxiety and panic attacks and admitted to not asking much because she gets worked up. One woman described feelings of panic trying to find a toilet.

One woman describes her situation as irritating and embarrassing but is relieved at the plan for surgery. Another woman feels that her embarrassment and feeling of being dirty are made worse by poor conditions at work. She also feels unpleasant and resentful at having to live with the problem and angry, cross and negative. One lady said she felt depressed due to lack of sleep secondary to nocturia. One woman felt she had less stress because she knew there was no cure but felt shy and withdrawn. Another participant described humiliation, anxiety and embarrassment but is now feeling more positive.

One woman says she feels like her body is going to pack up. She feels desperate, appalled and feels like life is closing in. Emotion was recognised by some of the participants as a cause for their bladder problems. Depression and feeling low were described and one woman found that being wet and using towels was getting her down. Another subject described her problems as degrading.

One patient expressed a fear of being alone at the outpatient clinic, preferring to wait back in the waiting room rather than alone in the consulting room. Fear was expressed by several subjects in relation to getting into relationships. Embarrassment was a very common emotion. Embarrassment about having UI, speaking about it, having urodynamics and staying in hotels because of the bed sheets being wet. Leakage outside the home creates worry. One woman worries about having to wear tissues when walking. One woman said the bladder is on her mind in the morning and she cannot walk well and worries about getting to the toilet on time. One woman says she was worried she may need an operation. Another woman was worried because she had no urge to have sex after her operation. Some subjects found the thought of their treatment nerve wracking while others found complications of treatment stressful.

Many women are self-conscious, self-conscious of movements, self-conscious at someone's house in case the pad will not hold and conscious of leakage at work or in cars. Some subjects acknowledge that they have a psychological problem in general, while one subject feels there is a psychological problem as soon as she goes out of the house. One woman describes putting herself to the test by trying to hold on as

long as possible and not going to the toilet. Another participant feels that stress contributes to her problems and has noticed that her bladder was better on holiday. A general negative emotion expressed was life being a nightmare. Negative aspects to treatment were expressed with one participant feeling negative towards the physiotherapist who she thought was laughing at her.

One woman felt upset when telling her GP about her bladder problems. Another woman describes how she felt awful not being able to take a drink on a night out on holiday as people were looking at her. Other negative feelings include feeling horrible, vulnerable and lethargic because UI is preventing exercise.

One woman was crying because of leakage and having to change in public toilets. Another woman says she is not happy with the way she looks and wishes to drink a lot of fluid so she can diet but feels she needs to restrict her fluid because of her bladder. Some people dwell on problems. Other negative emotions include, feeling negative, bad, not confident, degraded, sad, fed up, tired, isolated, old, nervous, inactive and having low self-esteem.

Positive emotions include feeling great after treatment. Women express happiness after treatment and some at being able to stay in hotels after treatment and not having to carry pads around. Hope, satisfaction, having fun, elation, feeling good, appreciative, normal, in control, safe, confident relaxed, positive, healthy and fine were positive emotions expressed. Several women expressed hope, hope that tablets will work and hope that everything will be fine, hope to stop the catheter and

go back to normal and hope that things will change. One participant was looking forward to a new tablet. Another said that she never gets depressed and expressed relief at being believed.

Perception of the condition of UI

UI is perceived as a condition of older women to such an extent that this stigma prevents younger women seeking help[27]. UI is considered a socially unacceptable topic of conversation[27]. It is seen as unclean and Muslims are denied prayer if they leak, until they can clean themselves[25]. The women felt sinful and had low self-esteem[25]. UI can also be seen as a problem of personal control[27].

Self-image

UI has an impact on self-image[27] with some people focusing on the ways in which UI has affected their life[27]. Sufferers can hate their bodies and feel they are to blame because they have not done pelvic floor exercises[27]. Low self esteem comprises shame, dirtiness and embarrassment[25]. Additionally feelings of loss of self-control result in shame and humiliation, fear of ridicule, secrecy and difficulty accepting incontinence and diminished self-concept[25]. Women comment that their UI has made them feel older than they are. People with UI often feel they are not normal. One participant wants to be able to open her bowels normally. Another wanted to stop using a catheter and go back to normal. Perfection was construed in some repertory grids.

Sexuality is an issue, which affects self-image. Some are worried because they have lost the desire for sex since surgery. One woman who has not been able to have sex

for 11 months states feeling she is not a proper woman and cannot give her husband what he wants. Another feels her femininity is affected by going to bed in pads. One woman had split up with her husband but was worried in case they got back together and she was not able to have sex. One of the interviewees conversely said she had not let UI affect her sex life and that she was on her third partner. Things other than UI were given as reasons for having problems with sex such as not being able to use hormone replacement therapy or painful sex after a colposuspension.

Confidence is often affected with UI. Some people wear pads to increase their confidence but conversely people hope not to need pads so that they can feel more confident. Other people's attention on their bladder reduces confidence.

Self awareness

People are self-conscious of themselves and their bladder. This overlaps with themes of confidence, self-image and hygiene and also impacts on self worth.

Trigger for presentation

People present because of their own experiences and feelings and also other people's influences. Some reasons for presenting include feeling fed up, noticing a smell, feeling something was wrong with her physical structure, leakage affecting activities and inadequate self-containment measures. One woman presented because she thought she needed an operation. One woman was very conscious of her movements so she saw her GP after trying to overcome it with exercise and muscle control unsuccessfully.

Some women's children or grandchildren complain of smell or make jokes. Some women presented to their GP with other complaints such as bleeding, swollen feet and bowel problems. One woman was prescribed the gym but she could not go because of her bladder problems and this is how they came to light.

One woman described a telephone helpline and felt it could be better advertised. Seeking help was prompted after talking to another patient. Another saw an advert by a drug company looking for volunteers.

Barriers to seeking help for urinary incontinence (UI)

The stigma that UI is an old woman's condition prevents younger women seeking help[27]. Incontinence is seen as a socially unacceptable topic of conversation thereby inhibiting presentation to health professionals[27]. Other barriers to help seeking include embarrassment[25;118], shame[118] and generational differences in attitudes towards disclosing personal matters[118]. Older people accepted UI as an inevitable part of aging that they expect to manage themselves[118]. Language is a barrier to seeking help and obtaining advice as studied in a group of Pakistani women[25]. Reasons for delay in seeking help included:

- A reluctance to accept it was happening to them
- An unwillingness to discuss an 'embarrassing and personal' problem – particularly with a male GP
- Feelings of shame and guilt, lack of knowledge about where and how to seek help

- An assumption that nothing could be done to treat incontinence especially as continence pads are advertised
- An assumption that incontinence was something to be tolerated in old age
- There was also a misconception of the benefits of pelvic floor exercises

Embarrassment delayed presentation and one woman felt that a questionnaire paper could be sent out to reduce embarrassment at the consultation. She also felt she was asked medical questions but not how it affected her social or sex life.

One woman found it difficult because she works for her GP so she did not present until there was a locum doctor on duty. There was sometimes a reluctance to tell a male GP and a perception that the female GP can be difficult to get an appointment with. Some felt that their GP had very little knowledge and referred to the practice nurse. There was also denial with a refusal to believe in the presence of UI and thinking it may be a psychological problem. Some felt UI was their own fault.

Awareness

It was felt there was not much information but that there was an increasing awareness. Most publicity was from pad manufacturers. An incontinence article prompted discussion with a spouse and then an appointment with the GP. People had been unaware that there was a specialist continence service in their area.

Information

Information was accessed through the manufacturers of continence products and national helplines. It was felt that there was very little information at the GPs. Women

in the focus group felt that it was likely due to underfunding and therefore the commercial sector was responsible for most of the information. They acknowledged that continence could lead to other issues with cost implications (depression, breakdown of family relationships) for medication or psychiatric services. In the event of unlimited funds the focus group wished for more information and increased awareness wherever possible, especially at GP surgeries. One person said she would be embarrassed to pick up a leaflet even in the GPs but would consider it if it was in the consulting room. Other suggestions were clinics, libraries and supermarkets. One person felt that the local pharmacist was very helpful regarding pads. It was felt Information should include local contact details.

Patients' experiences of UI treatment

Experience of UI treatment is divided into themes as follows:

- Expectations of UI treatment
- Care
- Communication
- Staff
- Investigation
- Coping and self-management
- Information
- General advice
- Pads
- Physiotherapy
- Bladder retraining

- Medication
- Surgery
- Injections
- Stem cells
- The future
- Issues for caregivers

Expectations of UI treatment

There were wide ranging views and experiences of treatments. There were both negative and positive comments. One woman said that her GP had tried things that made no difference. One woman took ownership for her own treatment saying that she was trying her best.

Some participants have negative expectations that there is no cure or expect complications. Some expected to be helped and others expect the bladder to be fine in the future. Some women thought treatment would be quicker. Some women expect to be continent while others aim to be able to manage comfortably. Surgical expectations include a cure for UI, a life improvement, something miraculous, not wearing protection, voiding problems, able to do sports, not to be conscious of the bladder and able to get on with life. Some women did not know about treatment and thought they just had to put up with problems. One expected immediate success but problems occurred.

Care

Patients give more credit to QoL, interpersonal and organisational aspects of care such as access, availability and convenience[116]. Some people just want information regarding causes of incontinence and self management[26;116]. Inhibition, language barriers and perception that health professionals are unresponsive to problems affect communication and comprehension. In a group of Pakistani women, satisfaction was increased when an interpreter was used and if they were seen by a female clinician, particularly if an examination was required[25].

It is suggested that health beliefs influence improvement because self reported wetting measures improved in all groups of one study (comparing control, education and PFMT)[162]. It was suggested that nurses teach about UI treatment and address psychosocial aspects to minimise the impact of UI[117].

Some women had private care for various reasons including the level of distress and NHS waiting times. There was a perception that private care was quicker but also there may be a faster recourse to surgery which one woman regreted.

Some women felt, when it came to treatment, they were being put through hoops and it was a waste of NHS money. Some participants highlight their own roles in their management. One lady describes how she was allowed to decide her treatment regarding the use of catheters. Another said she requested a specialist. One woman

admits that she did not ask any questions before her TVT operation. She saw it as a week off work and a way to get some attention from her husband.

There was a positive comment on the hospital that it has a caring feel as opposed to one her mother had been in before. There were negative comments regarding referrals, waiting lists, waiting times, changes of consultant and changes of medication. One woman observed how the consultant in the NHS appeared rushed. One woman described an outpatient experience where she felt embarrassed as she lay on the bed and leaked in front of the consultant. Another woman commented on the history taking she received not remembering being asked questions about whether it affected sex or social life, saying it was more medical.

There were negative comments about information regarding surgery. One said she was not told what to expect postoperatively. Another anxiously waited for her six-week review. Women did not always feel they had a choice of treatment. One woman said the TVT sounded simple. She was not given any other options and went along with it because the consultant was recommended.

Information giving was also seen as a very positive aspect of care with people being helpful and informative. Women made positive comments about the way in which they were treated. They appreciated their privacy being respected. When women felt that their GP understood this was appreciated, even if their knowledge was incomplete. Women appreciate the determination of the hospital staff to help and

make sure you have as good a life as possible. Some women said that their GPs did not do anything initially. Most were referred and some were given leaflets.

People feel that continuity of care is important. Some saw discharge as proof they were better and a cause for celebration. Other feel that the review appointment is a crutch they can lean on and wish to keep coming back. Some were worried about what to do if they were discharged and their problems returned and how long they may have to wait if re-referred to hospital. Some felt the nurses inspired them with confidence to manage things themselves but they could be contacted if necessary. Some felt better knowing they could contact staff directly if they had any problems. One woman was reluctant to contact them in case she would be disturbing a busy clinic. Relationship with staff is valued and this was discussed in both the focus group and in interviews.

Some women in the focus group attended a patient support group and felt it had positive benefits. Participants did not feel that problems have to be endured in isolation. Talking in the group helped people to discuss the problems outside the group e.g. with their husbands. Some felt it should be more widely available.

Communication

The importance of the language used to explain symptoms and procedures was highlighted. Examinations and investigations can be humiliating and degrading but information can put people at their ease. Inpatient stays were seen as marvellous allowing time for information to sink in. Women wanted easy to understand

information and liked when questions were encouraged. Some focus group members recommended bringing paper to write down instructions given at the appointment.

Not everyone understood what would happen at physiotherapy. Some thought it would be group exercises in a gym requiring special clothes. There was a fear of telling nurses of a setback in case there were no more treatment options resulting in discharge. One woman complained that she was not told what she needed to order when discharged from hospital. Another woman commented that getting through to the GP is difficult.

Some women felt they were not told things about surgery or they did not understand what they were told. Several did not understand they could be left with urge after SUI surgery. One woman said there was nothing her doctor said which made her afraid of surgery and she would have liked more information and may not have had the operation. She understands now that there are other treatments.

One woman felt that medical people might not listen because they have heard it all before and others thought in hospital people do not have time and are busy. One woman said that a doctor shouted at her for drinking caffeine and used language she did not understand. Other suggestions included women talking to women and an informal atmosphere. One woman did not receive her appointment and had to phone up.

Staff

Staff were mentioned throughout the interviews. Positive staff qualities were honesty, persistence, supportive, good communication, caring, listening and appearing to believe. One woman stated she was not satisfied with anything before her current consultant and because he has an interest, this helps her. The nurses were praised for explaining everything. One woman said she felt better because the doctor seemed pleased with her. There was good communication and the nurse clinic was felt to be good as they have more time to explain things.

Sometimes women were able to recall things said to them in consultations that seemed to have a negative impact on them. There were comments about lack of continuity of care and a desire to see their consultant. One participant also detected friction between staff. Negative staff qualities include dishonesty, concealment, not appearing concerned, an element of secrecy, inapproachability, being uninformative and not seeming to know what the problem is. One woman who was told she would have to live with her bowel problem felt resentment. Another was told there was nothing they could do for her. Some participants noticed reactions of staff or commented on missed things like an ovarian cyst or tape erosion. There were several other comments about staff.

Investigation

One woman felt that urodynamics was of no benefit. Video urodynamics made one participant feel horrible when she had a big leak. Another woman felt that urodynamics was very slick. One woman was not pleased that her explorations were

all normal. She wished something would show up so that something could be done. Urodynamics was described as embarrassing and not unpleasant.

Focus group participants felt that tests should be carried out in the hospital environment and appreciate having a specialised hospital with the environment discretely labelled alongside other women's services.

Coping and self-management

The maintenance of normality may involve a great deal of work[27]. Careful anticipation and mindfulness become a way of life[27]. The main aim is often to reduce risk of incontinence episodes[25;27]. This includes obsessive bladder emptying, toilet mapping, route planning, selecting safe outings and activities, avoiding dangerous movements, fluid and clothing restrictions[27]. Managing incontinence episodes is also important[25]. Some women buy pads and pants in bulk and carry spares[27]. Other practicalities include protecting soft furnishings[27].

Hygiene is a concern and women check themselves for odour with some using vaginal deodorant and deodorised pads[27]. Some clear up immediately and throw away soiled underwear[27]. Pads may be changed for leakage or to manage smell. Some women wear pads for peace of mind or to increase self-confidence even when they are usually dry. Some women bathe or shower more often. One woman wears two pairs of pants to give her extra support but finds this uncomfortable and does not do this when at home. She carries her own toilet paper because she fears that public toilet paper will infect her prolapse. Some people carry wipes with them.

One woman commented on how postoperatively she changed from pads to panty liners. Some women wear pads for certain situations only. Women may wear panty liners initially and then as the problem gets worse progress to thicker pads. Some women worry that the pad may be inadequate in public or on transport.

Women have also described wearing a hand towel under their pyjamas, putting a towel on the bed or on friends' sofas. Women choose clothes they perceive as easier. They may carry spare clothes, shoes, underwear or keep spares at work. Other devices have been described in some interviews. One woman brings a washing bowl to work to pass urine in. Her husband also made a device to help her pass urine by the side of the road. Self-catheterisation helped one woman cope with her discomfort. Another woman keeps a potty under the bed.

Coping strategies included muddling on, minimising and renaming it[27]. Some women pay studied inattention to it[27], therefore claiming to be satisfied with current management. Maintenance of secrecy is part of some people's management strategy[27].

UI is seen as a threat to self esteem and if self esteem can be maintained then a normal life may result[26]. Prayer helped to relieve stress due to incontinence in a group of Pakistani Muslim women[25]. People found support through humour, hope, personal motivation, prayer, friendship, physical aid from people or institutions and spousal support[117]. Problem sharing with other women was also valued[25].

Some women admit to a psychological aspect to how they cope. Some feel they do not have a choice and just have to cope or get used to situations rather than noticing them. Some participants keep busy to distract themselves from UI. One woman is determined not to give in to conditions and describes how previously she got herself a job as an act of determination not to give in to cancer.

Some restrict fluids generally and some in the evenings or when going out. Another describes the conflict she feels because she has to fluid restrict but also believes water is needed to keep healthy. Some women avoid alcohol or caffeine in particular. Some eat mints instead of drinking.

Women tend to avoid precipitating activities such as playing with children, coughing, laughing, physical relationships and sex. People make up excuses so they do not have to go particular places. Preventative micturition and toilet mapping is used in an attempt to control bladder problems. One woman comments that when she had an accident she used to get her husband to fetch her but now she drives and can find herself a toilet. One woman stopped most of her sport and relied on road running so she was near home and if her shoes were full she could get in the shower at home. One woman voids before a meeting but she knows that in bladder training she was taught not to go preventatively.

One participant copes with her bladder by treating it as a joke to other people.

There are specific examples of people coping in their everyday lives such as standing and waiting to get bladder control, sitting on the floor and trying not to pick the children up unless at their level. Some people feel they cannot cope or learn to rise above it while others grin and bear it. One woman uses an alarm clock to manage bladder problems at night without medication.

General Advice

General advice about food and drink was mentioned. One woman said she was told not to drink alcohol, which was not a problem. She was also told not to eat fruit but she says it is about a third of her diet and she really likes fruit. Another woman says she was given advice when attending urodynamics but does not feel she can defeat the problem at a practical level. Some participants found that avoiding tea and coffee made a big difference, even without other treatments. One woman was told to drink more fluid but was then going to the toilet. One woman wanted to drink a lot of water as part of a weight loss diet. She was especially keen to lose weight in case she needed an operation and also admitted that she was not happy with the way she looked.

Information

One woman said that her GP gave her leaflets. Some women felt that people were not aware that there are treatments. Another woman described a helpline she felt should be advertised.

Pads

Many of the women were using or had used pads in the past for leakage. There were many comments about changing and leaking beyond pads and also having to wear them all the time, which is different to wearing them for periods. One woman admits to wearing pads for psychological reasons to feel secure but they are usually dry. Several women commented on the expense of using pads. Pads are also discussed in self-management.

One woman worried about discovery via pads, putting used pads in other bins so the hotel cleaner would not see them in her hotel room bin.

Physiotherapy

Physiotherapy was considered a waste of time by one participant and ineffective by others. One woman admitted to not doing pelvic floor exercises wholeheartedly because they did not work before. One woman recalls how the devices fell out during physiotherapy and she found this humiliating. Another felt physiotherapy was difficult when they showed her. One participant felt her muscles were tight and the exercises did not help.

One woman found that through doing pelvic floor exercises she became more aware of her physical structure and that something was wrong. Toning tables were used by one participant to tone her body and she was told it could help pelvic muscles.

Many of the interviewees had continence surgery and therefore by definition should have had previously failed physiotherapy treatment. One woman felt she exercised too strongly and too often. One felt negative towards physiotherapy and the treatment. One woman felt that the physiotherapist was laughing at her and this made her feel bad. Another woman was given treatment to do at home but she stopped because of the way it made her feel.

Bladder retraining

There were mixed opinions on bladder retraining. One participant does not have any faith in bladder retraining alone but feels it is better with tablets. Another woman was advised to wait five minutes before going to the toilet in the night but she did not want to do this in case she could not then get back to sleep. She tried staying awake in the night and setting an alarm but this was of no help. She also tried bladder training in the daytime but has other things she would rather be doing and does not feel she is a good candidate.

One woman said she found bladder retraining difficult. Another said that she needed to go to the toilet within 15 minutes of drinking fluid. Another woman felt that it made a big difference. One participant was motivated saying she was giving it her best shot. Some participants had undergone inpatient bladder retraining but complained that they did not know what to do the first day, which they felt was a waste. There was a feeling on the ward that not all the nursing staff was enthusiastic about bladder drill. One woman acknowledged that it was challenging but felt she benefited greatly. Inpatient bladder retraining was felt to be ineffective by one participant whilst another

commented that it was no good as it was not a typical week. One woman did not want to wear pads, which is part of monitoring leakage as it was a step backwards. Some women compared themselves to other patients who were in hospital at the same time as them, seeing people who were worse than them and also seeing other people improve with retraining.

Medication

Several of the participants tried tablets for their bladder, sometimes prescribed by their GP. It was not always clear if they were anticholinergics for OAB or duloxetine for SUI.

For some women the problem was lack of effectiveness or side effects. One woman said she tried lots and none worked. One did not see detrusitol helping but it was only two weeks. Side effects were a problem for some women such as dry mouth, acid reflux, nausea and urinary retention.

Drug reactions were experienced by one woman who still says she prefers drugs to surgery. Other negative things attributed to tablets were rash, diarrhoea, thirst, weight loss and a chest infection. One participant felt the tablets helped and she used them if she was going somewhere. One participant stated that the side effects were a bigger problem than the incontinence. She also says she is compliant; doing what she is asked even though there is no difference. Duloxetine is also used as an antidepressant and this appeared to put some women off. Some people did not want tablets whilst others were keen for tablets. There were positive and negative

experiences of oxybutynin patches. Trospium was felt to be no help for one participant. Duloxetine had just been commenced a few days previously by one participant who has no side effects and is looking forward to seeing if it helps. One participant felt HRT had helped her nocturia. Some women were on antibiotics for UTIs.

Surgery

The majority of women who were interviewed and had surgery had a TVT for USI. Some had other operations including colposuspensions, vaginal repairs and hysterectomies. Not everyone had undergone surgery. A wide variety of surgical experiences are summarised in the following subsections:

- Decision for surgery
- Expectations of surgery
- Experience of surgery
- Good outcomes/positives
- Complications/negatives
- Postoperative behaviour
- Decision for surgery

People vary greatly in their desires for surgery. For example one interviewee hopes she can avoid surgery with medication and exercises whilst another believes it is better to have surgery when younger and healthier. One woman said she was apprehensive about having surgery and saw it as messing with her body and would prefer no intervention first. Another woman feels that without surgery things will get worse and she would not feel human and she would not see the point of being

around. One woman who had previous surgery feels relieved that she is going to have more surgery and wouldn't want tablets.

Some women who were advised to have surgery made various comments. One woman felt as though she should have the operation without a lot of consideration. Her consultant suggested TVT straight away telling her it would be amazing, change her life, not like the old days. She would be out the same day she did not get any other options.

One woman says she was told to have an incontinence operation along with her hysterectomy as she would probably need it in a couple of years. She was fine for a couple of years after surgery. She was then advised to have a further operation (vaginal repair) and has had voiding difficulties since.

Some women relate their decision for surgery to investigations. Some women did feel that they were prepared and informed of possible complications.

Some women who were advised not to have surgery made comments. One woman said that her consultant does not feel it would help; that she is not bad enough for surgery and surgery may make things worse. One says she would do anything not to have surgery. Some women are embarrassed that they need UI surgery and try to conceal the fact that they are having a bladder operation such as having it when off work and not telling people what they are doing.

- Expectations of surgery

Some women felt prepared for complications such has having ISC lessons, or the possibility of making urge worse. One woman was told her colposuspension would last 10 years and it did.

- Experience of surgery

One woman commented that she was very sick the morning after a TVT. One woman was sick and distressed and was in hospital for three to four days. She was sent home with a bag but woke up with excruciating pain and almost fainting with a UTI and was sent to the hospital. One felt the procedure itself was not a pleasure but it was not degrading. It went very smoothly. One lady who was expecting day surgery was late having surgery and had to stay overnight and it was a bigger operation than she thought. Because it was a local anaesthetic she had assumed it was minor. One woman said when she came around from the anaesthetic she was sick and cold and thought she was in the morgue.

One woman praised her surgeon. There were several anaesthetic comments with one woman commenting on how reassuring the anaesthetist was. There were positive comments about local anaesthesia as they could talk through the operation and did not need to stay in bed like women who had regional anaesthesia. They were also able to avoid feeling woozy and able to have a cup of tea within an hour.

- Good outcomes/positives

People's positive outcomes of surgery included a reduction in frequency, ability to resume exercise, able to cough, laugh and drink, improved self-confidence, less embarrassment and a reduced need to plan ahead or wear pads. One woman felt like she had a new bladder. Some said the operation had worked, was a cure and a success. One said it was amazing how she got her life back after a little bit of tape. There were comments about not needing to wear pads anymore and boosting confidence. One woman felt her treatment had been wonderful even though she still had a catheter and has problems passing urine. Another woman explains how she feels she must put her trust in her health professionals.

- Complications/negatives

Postoperative complaints included needing the TVT cut, urinary retention, abdominal pain, tape erosion, bruising, swelling, difficulty passing urine, slow stream, incomplete emptying, catheterisation, pain and having to stand up to empty the bladder. One said her operation was not successful.

One participant who was performing ISC was annoyed she had to pay for the catheters. One woman had a catheter for 10 days but did not like it. She would only go out with her husband and was terrified of it coming out when she was climbing in and out of the bath. Another participant found ISC difficult but got used to it and accepted that everything has to be learnt. One participant mentioned she has to do ISC but there are no facilities for this at her workplace. Some women had to have their TVT cut for voiding dysfunction and some were upset at this. The actual catheters were sometimes an issue with the GP prescribing bigger catheters than the

hospital. One woman commented that she was unaware she could get infections with ISC.

One participant said she is fine doing ISC at home but will not do ISC in a public toilet. Another woman said she has a mental block with ISC. She feels this was a combination of a family member having cancer and one of her friends told her she could perforate her bladder doing ISC.

One woman did ISC to prevent a leak when she had urge about seven times a day. Another participant feels she would prefer an indwelling catheter so she can have more freedom and to avoid discomfort and pain.

There were negative comments on ISC, having to do it and it not being pleasant. The thought that it was short-term helped one woman to cope with ISC. One woman preferred ISC to leaking. Some women felt that the suprapubic catheter seemed less drastic and easier to cope with. One felt that it was not too obvious and that work colleagues would tell her if it was obvious. Another woman commented that she was not ready for something permanent. One woman praised the discreteness of the catheter company.

Ongoing urge was an issue for some women with leakage, lack of control having to plan everything around the toilet, fluid restricting and performing preventative micturition. Some were worried in case something was wrong with the operation. One woman wanted to know what was causing the urge as much as resolving it. Some

women experienced pain and discomfort postoperatively. One woman was sore for a few days, missing work and her own birthday celebration. One woman who had pain after a TVT turned out to have an ovarian cyst.

Some women have ongoing leakage needing pads or are cured and then symptoms return. Some people complain of more UTIs after TVT. One woman experienced tape erosion describing how her husband was ripped during intercourse. She said she was initially told it was scar tissue and given anaesthetic cream and tablets. After the tape removal she still had pain on intercourse, groin pain and leakage.

One woman post-TVT said she lost weight, stayed at home for a couple of weeks, avoided exercise and appeared to regret surgery. One lost the urge to have sex postoperatively. One woman was surprised at the blood loss with TVT and said this was not explained to her. Another woman describes a dent where the sutures were, which was removed under local anaesthetic.

Some women had other procedures they related to their UI with one woman saying that her hysterectomy helped a bit. A cystoscopy and bladder stretch helped one woman for a little bit. One participant felt her hysterectomy was not helpful for her bladder and she had believed that this is what the hysterectomy was for. For one woman a Marshall Marchetti operation made everything worse and she thinks she was a guinea pig.

- Postoperative behaviour

People found that they were able to wear different clothes. Some feel much happier that they do not have to carry pads around and that they are able to get on with life, go to the gym and pursue other interests like joining slimming clubs. Some feel that their previous problems are not a problem anymore. People are able to go on holiday, have improved sex lives with more spontaneity. Self-confidence is also boosted. Others still have to toilet map and learn ways to deal with the bladder so that it suits life.

Injection

Some women had injections. One was not sure what she had and another said she was referred for injections but then found they were not available.

Stem cells

One woman said that there was some work on stem cells and then an operation would not be needed.

The Future

One woman said she would have a further operation if there were a 70% chance of no pain and light leakage. One woman mentioned cognitive psychology, which she had previously for pain. She explained she learned things like instead of picking lots of spuds, just pick a couple and relax and enjoy the garden.

Issues for care givers

Issues for care givers include the struggle to balance self, care giving tasks and role expectations[117]. There are financial concerns regarding using hired help. Caregivers suggestions included physical modifications, accepting help and finding time away from care giving[117]. Care givers felt that nurses should educate patients about UI and address psychosocial aspects to minimise the impact of UI[117].

CHAPTER 16

ADDITIONAL MEASURES FOR IMPROVING MANAGEMENT

16.1 Introduction

Through studying the literature review, focus group results, repertory grids and interviews it became clear that there are numerous things that patients feel could be improved upon. Although this was not a primary objective in this study, this is valuable information and is therefore being included in these results as it may improve management of this patient group. These factors are outlined below with suggestions for managing them.

16.2 Findings

- **Information giving**

It is clear that women want more information[116]. This includes information for the general public who are unaware that UI is present amongst all age groups and how and where to seek help. Advertising was suggested outside the healthcare environment such as at libraries or supermarkets. Subjects felt that this would improve presentation rather than suffering in silence. Some literature suggested that women who do not present may have a preference for self-management and that

written information was effective to this end. It was felt that local contact details should be present in the written information. There was uncertainty expressed about what was actually involved in various treatments e.g. inpatient bladder retraining, physiotherapy, surgery and people think they should have been better informed.

- **Preoperative preparation**

This could be improved to include information, alternatives, risks and potential complications. Some of the women did seem to be well prepared but were still dissatisfied when they had urgency or needed to do ISC. It may be necessary to explain how these can be treated postoperatively so that they know there are treatments available. It may be worth seeking preferences for types of treatment for individual women and trying to work with this. If the recommended treatment is something they do not prefer then they may need additional time and information to decide. A leaflet outlining all available continence treatments may be useful. This could include the indications, pros and cons and may help to take the patient with the clinician on the decision journey.

- **Nurse teaching**

It has been suggested that nurses should teach patients about treatments for UI and stress psychosocial aspects that minimise the impact of UI[118].

- **Support for caregivers**

Physical modifications, accepting help and finding time away from caregiving[117] were found to be beneficial for patients and their carers.

- **Addressing psychiatric symptoms**

Psychiatric symptoms predate urinary conditions in some patients[177]. Psychiatric treatment may help UI[178]. There may be unrecognised depression or somatisation occurring[171]. If masked depression could be identified and treated this may prevent unnecessary traditional continence treatment being prescribed. This may be especially pertinent to those who have normal urodynamic studies[191].

- **Assessing personality factors**

Introverts (on the EPI) respond better to bladder retraining than extroverts[128]. Patients with symptoms but no signs had high neuroticism and depression scores[191]. Those with high neuroticism may be better treated with psychological therapies such as CBT or hypnotherapy.

- **Goal setting**

Unrealistic goals could be addressed before treatment. It may be possible to assign goal ownership scores in order to improve motivation before treatment. This may improve compliance and continuation with treatment rather than defaulting if poorly motivated[198]. While there has been a vogue for research into goals related to UI, patient satisfaction was only moderately related to goal achievement[14].

- **Assessing treatment seeking types**

It is possible to screen people for their treatment seeking type[22]. Those who are not treatment seeking (type R) may benefit more from adjusting to their environment than treatment seeking types (type S)[22].

- **Patient support groups**

The focus group comprised some members already attending a patient support group. They found that attendance helped to reduce their feelings of isolation. It also got them used to talking about UI, which in turn helped them to bring the topic up with other people such as their partners. In the literature and interviews there were suggestions such as talking about the problem might help, women talking to women might help, and women had sought comfort and support from talking to other women. One interviewee suggested putting everyone in the waiting room together and being late so they are forced to talk to each other. Some women having inpatient bladder retraining observed how other people are worse than themselves and this helped them. They also were able to see how others were improving with treatments and this improved their own motivation. There was an observation that healthcare professionals, especially doctors, can appear rushed and have limited time in the NHS. A self-help group facilitates discussions amongst women and also would be an opportunity for healthcare professionals to address a number of women at once.

- **Simple advice**

The focus group suggesting bringing paper to the consultation to write down instructions.

- **Exercise classes**

Some women felt overweight, affecting their body image and self-esteem. They were not able to exercise because of SUI. Some women wanted to be able to exercise and felt lethargic because they were missing their exercise. It has been suggested that exercise is a treatment for depression and possibly anxiety and therefore there may be additional benefits to facilitating exercise. Women will not go to exercise classes or out in public because of fear of visible leakage or the need to repeatedly leave the class or swimming pool because of frequency. Exercise classes held for women with UI where they know everyone in the class may leak or have to go to the toilet may be advantageous. This could even be combined with the patient support group.

- **Identify and address other medical problems/issues**

Some of the interviewees were bothered by problems with their bowels, arthritis, asthma, pains etc unrelated to their UI. If these are not addressed then overall psychological well being may not be optimised. Referral to the appropriate professional or highlighting these factors to the GP is likely to be beneficial.

- **Telephone helpline**

Some patients had telephoned helplines rather than approaching their GP first. They felt that this was useful even if the helpline told them a little about the condition and gave them the confidence to contact their GP.

- **Questionnaire**

It was suggested in an interview that embarrassment prevented people explaining all the ways that UI affected them and that a questionnaire completed at home would have made this easier.

- **Primary care contact**

Some people felt that their GP did not do anything and they had to present several times. Some felt that their GP was very understanding and this was helpful even though they did not know what to do. Most women were eventually referred to the continence services. It would be useful for there to be increased awareness of UI in primary care so that when someone mentions UI it is acted on at their first presentation. The ongoing taboo nature of UI means that it may take a long time for someone to admit it and if they are not steered in the correct direction it may be years before they mention it again, if ever. Ideally each practice would benefit from a GP or practice nurse with an interest in UI and then a clear route of information giving and/or referral to continence advisor, physiotherapist or gynaecologist/urogynaecologist.

- **Aspects of care**
- Continuity of care - Women appreciated continuity of care. There was a desire to see 'the person in charge'. It can be a challenge to provide continuity within health service constraints. Nurse led services may be better at this than the medical model of care.
- Time to talk - There was the impression that doctors are rushed in the NHS. Again the nurse led service may help in this manner.

- Respect of privacy – This was appreciated.
- Discharge from care - Some woman are pleased to be discharged while others fear it. Those who feared it in the focus group were reassured by others who were discharged but knew that they could telephone the nurses for advice.
- Allow time for recovery – Some women felt they would have liked longer in hospital e.g. after TVT.

16.3 Implementation

Some of these factors may be relatively easy to access such as information giving and respecting patients privacy. Others may be more of a challenge such as addressing personality factors. This is, however, a useful combination of suggestions drawn from the literature, focus group and original interviews.

CHAPTER 17

CONCLUSIONS

This chapter was presented in part to the British Society of Urogynaecologists in 2006 entitled 'Striving towards tailored urogynaecology management plans'[2], to the International urogynaecological society (IUGA) in Athens entitled 'is there a place for cognitive behavioural therapy in urogynaecology?'[4], to the UK continence society in 2007 entitled 'Treatment planning in urogynaecology Can we do better?'[6] and published[1].

17.1 Interpretations of the results

17.2 Limitations

17.3 Future research

17.1 Interpretation of the results

There are a great many themes relating to UI, which is a complex problem. Themes from the literature, focus group, repertory grids and interviews show some overlap, but no one methodology is capable of capturing everything that bothers women with this condition. This study has been very useful to bring all of these themes together. This is the first stage of the development of a tool to inform treatment planning.

There are many aspects of management of women with UI, which can be improved upon (Chapter 16). Some of these can be improved with immediate affect since they

constitute recognised good practice such as respecting privacy and information giving. Other areas are novel and would require development and evaluation.

The challenges of measuring outcome are clearly highlighted in this study. The related ‘t’ test on the KHQ scores clearly showed that Group 3 were highly significantly improved on their total scores following surgery. The KHQ is designed to be looked at in domains rather than as a total score, however, the overwhelming difference in total score suggests a high degree of improved quality of life. When this group were looked at as individual case studies most of them had factors causing them ongoing concern. Surprisingly some women who were troubled by postoperative complications and felt things were as bad as, or even worse than before surgery, were pleased they had their operation because they had tried to improve their situation. Some of those still experiencing bother did not regret their operation and would recommend it to a friend. This indicates that the KHQ is not sufficient to capture all the factors relevant to this population.

The literature review revealed many links between psychological conditions and bladder conditions. Despite this, studies on psychosocial interventions in UI are rare and have not been adopted into clinical practice. This study explores psychosocial aspects of UI with a great many themes related to emotion, self-image and confidence. It may be possible for some of these aspects to be addressed by psychological methods such as cognitive behavioural therapy (CBT).

The repertory grid technique was a well-accepted, useable and useful research methodology for this study. While the qualitative interviews provided rich accounts of UI they are very time consuming and the data is quite challenging to handle. The repertory grid, on the other hand, is represented in a single grid and it is possible to see at a glance the terms in which the subject is thinking, without direct enquiry.

17.2 Limitations

There is an ongoing difficulty in defining cure. There is no simple way to measure who is cured, happy, satisfied and dry. It was attempted in this study by using a combination of urodynamics, VAS, repertory grids and interviews but the lines between cured, satisfied and dry were extremely blurred. It was hoped to clearly divide patients into satisfied and not satisfied and study these groups but this dichotomy is not real. Fascinatingly there are women who have deliberated long and hard about whether to have surgery or not and have had it and had numerous problems postoperatively and are dissatisfied with their outcome. Surprisingly they are still pleased they had their operation and would recommend it to others! It may not be possible to simplify people into categories and it may be of more value to pay attention to all aspects of the multifaceted person with UI.

Some of the cases in the preoperative group did not go ahead with surgery. Whether they changed their minds after the interview is unknown. Some did not attend for their postoperative evaluation and no conclusions can be drawn about them or their treatment experiences. The interviews were limited to those willing to participate and speak English.

The study group 3 was not large enough to perform regression analysis to identify preoperative predictive factors for cure. Given the difficulty defining cure this is even more of a challenge. While most of the measures in the study were of value the situations affected by UI list was not useful. This is because of inconsistent interpretation of the questions postoperatively. These questions were not used in the results. The pads use part of this questionnaire was useful and is included when looking at the case studies in Group 3.

17.3 Future research

Women whose incontinence is clinically cured continue to experience psychological problems and future research is essential to improve management outcomes. The next phase of this research is development of the treatment-planning tool. Development of a tool is a clearly defined process beyond the scope of this study. The themes discovered in this study are derived from several sources (the literature, the focus group, repertory grids and qualitative interviews). This variety and depth of exploration will add both content and construct validity to the final tool. The next stage would be to draw together all the themes into a very large, single questionnaire to be administered to a large number of women on presentation to the continence services. Their eventual outcome will need to be defined as successful or unsuccessful, a challenge in itself. A regression analysis can then be performed to measure the associations between factors on presentation and outcome. This could be performed for several different treatments, thus providing the information about

what factors on presentation are associated with successful and unsuccessful outcomes for a variety of treatments.

Given the strong link between psychological factors and UI there would be a strong case for incorporating measures to identify factors, which may also influence outcome or satisfaction with particular treatments. This could include the identification of masked depression or treatment seeking type. There may be certain benefits to applying tests to detect psychosocial problems, however, health status measures need careful evaluation and review. For example some designs and analytic strategies are more adept than others at assessing change[199]. This is important if choosing a tool to use in a population undergoing a therapeutic intervention. In evaluating the suitability of available measures, three features must be considered[200]:

1. Practicality in terms of administration, respondent burden, and analysis
2. Reliability in terms of the study design and group or individual comparisons
3. Validity, in terms of providing information about the particular health components of interest to the study

Psychosocial tests have been used in other specialities including oncology[201;202;202-207]. A short screening scale to identify UI patients who suffer serious distress would be desirable so that management can be improved. An example of a currently available tool is the Hospital Anxiety and Depression Scale (HADS), a self-completing scale, taking less than five minutes to assesses severity of anxiety and depression in somatic and psychiatric cases in primary care and in the general population as well as hospital patients for whom it was designed[208]. There are short-

form scales for use with other morbidities, which have value in identifying at-risk patients. Examples include the Short Form 36 (SF-36) and the Short Form 12 (SF-12)[124], the Psychological Stress Measure (PSM-9)[209], the Social Difficulties Inventory (SDI)[210], the Range of Impaired Functioning Tool (RIFT)[211] and the General Health Questionnaire[212]. No such tool exists for UI patients, but this would be a valuable tool in the clinical armoury, since it would permit routine screening of women to identify those who are most likely to suffer from psychological distress.

Screening for goal ownership has also been suggested in other disciplines[198]. Goal setting is of value in urogynaecology to establish what patients expect of their treatment[14;15]. This approach still does not help formulate individual treatment plans but it may allow identification of unrealistic goals and perhaps modification of goals could potentially lead to improved satisfaction with outcome. It is possible that goals may change over time and may be different before and after treatment. Low goal ownership was a predictor of dropping out of a program[198]. Perhaps if those with low goal ownership scores could be identified and have interventions that would improve their motivation prior to treatment they may continue with their treatment more successfully[198]. Hardiness is another measure that may be useful. Both general hardiness and subscales of commitment, control and challenge can be measured[213]. If any screening tool is to be produced then the UK National Screening Committee guidelines should be considered[214]. These are subdivided into criteria concerning the condition, the test, the treatment and the screening programme[214]. The pros and cons of any particular test must be explained to patients and not just administered[215]. Pros would include acquiring knowledge that could lead to a beneficial intervention

and cons would include the time taken to complete a questionnaire or discomfort or complications associated with a particular investigation. The population to be tested or screened must be defined and procedures to enable administration of the tests to those that will benefit should be clear[216]. In this study some women had goals that they could not achieve for reasons other than UI and require further investigation.

Psychotherapeutic interventions have been assessed in many medical conditions including asthma and diabetes[217;218]. Interventions include CBT, telephone based education and support programs. Psychotherapy and hypnotherapy in patients with incontinence are included in the literature review. One option would be CBT[4]. The theory behind CBT is that an event may lead to a range of emotions. It is not the event itself that produces negative emotions but the way in which the event is appraised and CBT addresses this[219].

To summarise, there is much work that can be done following on from this study to potentially improve the lives of many women. This study provides the evidence needed to justify further development of a treatment-planning tool and the introduction of psychotherapeutic measures into the field of urogynaecology.

CHAPTER 18

OVERALL CRITIQUE OF THE STUDY

18.1 Critique of the entire study

The study is a mainly qualitative, subjective, multi-method study set in a tertiary urogynaecology unit in the UK. As with all research there are positive and negative aspects and a critique of the study follows.

18.1.1 Context of the study

The background, overview and justification for the study were presented in Chapters 1 and 2. A comprehensive overview of the whole subject area of UI and its

management was presented in Chapters 3 and 4 and the design context was described in Chapter 5. The research programme recognised, from the outset, the significance of UI to women and the apparent failure in current management to address the condition to the satisfaction of patients. The taboo and complex nature of incontinence means that, in practice, sufferers' interactions with healthcare professionals may not adequately address their concerns. The background of the primary researcher was medical. In order to give the necessary psychological input and relevance in the field of urogynaecology the supervisors were involved throughout the planning and execution of the study and were from different disciplines – one with a medical background and the other with a psychology and health sciences background. This was essential in selecting the appropriate methodologies for this study. The novel use of repertory grids in UI was made possible by the previous successful experience of the psychology supervisor. Medical research is traditionally based on quantitative methodology with the randomised controlled trial (RCT) being the gold standard to which all other methodologies are compared[89], as discussed in Section 18.1.2. Other urogynaecology research has paid increasing attention to outcomes and experiences other than whether or not continence is achieved. QoL and goal research has been performed and useful tools such as the KHQ developed. Current QoL measures do not appear to be capturing the whole picture. This is because QoL data tries to place the individual on a scale and to fit them in as part of the population rather than recognise the individual variation within patients as a result of the previous influences on their personality. If tools are not measuring what they should then there is an issue with their content validity and/or application. Previous work in the area has focused on evaluating

treatments rather than directing treatment. This study was the preliminary phase of a treatment-planning research programme. This study itself did not result in a treatment-planning tool and it was never designed to do so. It was an exploratory study of unmet needs in the incontinent population. It is interesting that in the early studies that women who continued to complain of symptoms despite objective cure were dismissed as being unrealistic[78]. This paternalistic observation 30 years ago missed the opportunity to engage with patients at that time to try and identify where their treatment had failed in terms of matching expectation to physical outcome. In doing so there has been a failure to develop non-physical therapies to help these women.

The study's explorations were into UI in general and then the focus was narrowed to surgical management of SUI. The benefit of chosing a general group was to explore the whole area of UI and get a broad picture of experiences and issues. This was enhanced by themes from a focus group (Chapter 9) and qualitative literature (Chapter 8) to give a full picture. A study of USI surgery patients was performed subsequently. It is anticipated that study of all modalities of treatment will be performed in the future but surgery was chosen initially for several reasons:

- When surgery is performed this is a clearly identifiable time point by patient, clinician and researcher
- Other treatments may be multifactorial and it can be challenging to tease out which treatment is under study or causing which effect

- SUI surgery is expected to have its effects fairly quickly and therefore, for the subjects who were studied prospectively (Group 3), it was possible to perform outcome measures within the timescale of the study
- SUI surgery is quick compared to other treatments (such as physiotherapy or bladder retraining)
- Medication compliance can be difficult to measure as it is usually combined with other treatments. Compliance can also be artificially improved by being recruited into a research study making 'real life' medical management challenging to study

Studying surgical patients in this way also identified patients who have had technically successful treatment but continue to have problems in a linear manner. Additionally it identified women who have had physical partial success but have had resolution psychologically. These are the areas of special interest in this research programme.

The psychological context of this study is discussed in Chapter 7. Incontinence sits well in the realm of personal construct psychology (PCP) being of a highly individual nature and recognising that everyone's experiences are real, unique and valid. PCP is presented in Section 7.2. Previous work done in the area of UI experience was discussed in Chapter 8. That work was reviewed to see if similar work had been carried out previously and also as an exploration of the themes generated by other researchers for incorporation in the results of this study to add content validity to any future treatment-planning tool developed. Objective measurement, which has been seen as the gold standard for many years, is making way for other outcomes such as

QoL and goal attainment and this is reflected in the literature[14-16]. Where this study differs is that its aim was not to evaluate treatments, rather to inform and plan management via the exploration of individual patient's experiences.

The setting of this study is within a UK tertiary urogynaecology setting as described in Section 5.2 and the advantages of this centre follow:

- Good access to women with UI
- The facilities and accommodation were readily available to interview and investigate the subjects
- The infrastructure present in this setting provided for aspects such as privacy, car parking and chaperones when required
- The women were already using the service and this enhanced recruitment to the study
- All the subjects had experience of a variety of care providers prior to being seen in the tertiary unit and there was therefore a wealth of experience about various encounters, opinion and management of UI
- The unit offers all UI treatment modalities and therefore availability or personal cost to patients was not a confounding factor in treatment-planning
- The pre-existing patient support group and regular multidisciplinary meetings provided useful forums for formulating and communicating ideas related to the study
- The unit has a very diverse population in its catchment area. This would provide a good basis for including ethnic diversity in the future

The drawbacks to this setting follow:

- The pool of women available to the study was restricted to those who have made it as far as a tertiary centre and they may not have been representative of the overall population of women with UI
- There was no opportunity to examine women who have not presented with their symptoms or were being managed in primary and secondary care
- Using one unit only may have introducd biases into the system that the researcher may not even have been aware of. An example of this may be that there may have been commonalities regarding pre-operative counselling in the study unit and this may have differed from other units. This may limit the applicability of the findings to other units

These limitations are part of the reason that data collected from the literature were also included in the results.

18.1.2 Qualitative research

Most of the methods used in this study were qualitative methods. Techniques of qualitative research rely heavily on accurate reporting in a natural environment[220]. Table 5.1 outlined the differences between qualitative and quantitative research. The main instrument used was the repertory grid, supplemented by qualitative interviews. Qualitative techniques are not held in as high a scientific esteem as quantitative methods and this was discussed in Sections 5.3 and 6.11, although there is increasing recognition by both the medical profession and policy advisors that qualitative research and the subjective experiences of patients are of considerable significance[100] For new treatment approaches and interventions to be adopted into

clinical practice they need to be robustly researched. Evidence based medicine (EBM) is the cornerstone of good medical practice and consequently research studies must be set up to provide high quality evidence to clinicians. The gold standard in EBM research is the RCT. The RCT is considered the very best way to evaluate a treatment and is given the highest weighting in systematic reviews[70;98]. The factors that make an RCT strong are a large sample size (appropriately powered), random allocation to study groups and double blinding to the intervention. The results should be transferable to the targets population (if the populations' characteristics are comparable). The reasons for rejecting the strongest form of evidence, the RCT, for this study were:

- UI includes physiological, psychological and social factors and it is difficult to isolate these variables for study
- The phenomena studied are dynamic and difficult to control for the purpose of experimental study[97]
- Concepts such as healing, stress, coping and QoL are not easily isolated and controlled[97]
- RCTs seek to generalise while the detailed study of individuals is desired
- The RCT is limited in producing data that can contribute to the understanding of human experience and behaviour[97]
- The RCT is reductionist and can ignore needs and experiences[97]
- This study aimed to reach a deep understanding of UI experience and treatments and there was no intervention being evaluated
- Individuals each have a different story and experience and therefore it was not desirable to group or compare them in the way required for an RCT

- Each individual's experience is valid and generalisations are to be avoided and by attempting to group participants the subtelties and experiences would be lost
- Over simplifications may have led to missed opportunities to discover ways of helping women with their experience and management of UI
- There was no intention or requirement to blind subject, researcher or clinician in this study
- Sample size could not be calculated by a power calculation since there was no known quantifiable treatment effect

Therefore, given the purpose of this study, the RCT was clearly unsuitable; the research question demanded an alternative approach which captured experiential, subjective and individual data, which had not be pre-determined by the researcher. It was not intended that the results would or could be generalised to a wider population.

18.1.3 The sample under study

One of the important decisions in designing a study is what data to collect and from whom[97]. A sample is a subset of a population and is usually necessary as it is not usually possible to study the entire population[97]. By stipulating inclusion and exclusion criteria, the researcher can define the target population known as the study population. The sample is usually a subset of the study population[97].

For a sample to be representative of a population it should be randomly selected[97]. Random selection was not performed in this study because the purpose was to contribute to the understanding of a phenomenon and those studied were those that

could provide the required data. This is non-probablility sampling as opposed to probability or random sampling[97]. Factors that can influence sampling include the availability of and access to potential participants and resources[97]. Rigorous sampling procedures used in quantitative research are inappropriate to the nature and scale of qualitative work[97]. There are five types of non-probability sampling – accidental, purposive, volunteer, snowball and quota. Generalising the results to the population is not the main concern, rather the aim is to contribute to the understanding of the area of study[97]. The alternative methods of non-probability sampling include volunteer sampling, where the participants are self-selected and this is considered weak[97]. Some volunteers offer to take part before coming into contact wih the researcher, while others may be from a captive population and may volunteer because they feel a moral obligation, gratitude, fear of reprisal, fear of being labelled uncooperative or the need to conform[97]. Snowball sampling means that a respondent refers someone they know to the study who inturn refers someone else and so on[97]. This can be helpful where recruitment is difficult such as in sensitive areas but one drawback is that the participant may refer people of a similar background to themselves[97]. Quota sampling involves elements of purposive and stratified sampling where a researcher needs different groups in a sample to be adequately represented[97]. In this study a purposive sample was used where the researcher deliberatively chose who to include on the basis that those selected could provide the necessary data; this approach to sampling is consistent with Kelly's theoretical conceptualisation of subjective experience and PCT.

In quantitative research, data from randomly selected samples are generalized to the target population and sometimes beyond to similar populations and groups. The degree to which this can be done is known as external validity[97]. With qualitative research the findings may be culture specific, time bound and influenced by the interaction between researcher and participant[97]. This means that the findings cannot be generalised to other settings[97]. In quantitative studies the focus is on how particular views or beliefs are distributed in a population. In qualitative studies, researchers are interested in the range of experiences in order to obtain as complete an understanding of a phenomenon as possible[97]. In Section 6.2 the recruitment of subjects to this study is described. It was never the intention of your study to produce generalisable data, but rather in-depth, subjective information.

Sample sizes in quantitative research are determined by power calculations prior to commencing quantitative research such as an RCT. Power calculations are based on an expected treatment effect and if a study is underpowered then a treatment effect may not be observed. In quantitative research larger sample sizes are generally considered to be desirable, although for efficiency the smallest size required to show significance is perfectly adequate. While quantitative research uses large samples and probability sampling, qualitative research typically involves small, non-probability samples[97]. A smaller sample is more suitable to collect more and in-depth data from participants[97]. In qualitative work it is the purpose for which the sample is required which determines how many subjects are required[97]. Too small a sample is unlikely to provide a range of experience if this is what is required. Too large a sample may mean that saturaton is reached early and time is wasted collecting further

information[97]. Qualitative work is concerned with individuals and each subject's experience is equally valid. It is not uncommon for qualitative research to have much smaller sample sizes than this study[25-27;117;118] and even a single subject can be studied using repertory grids[108]. As described in Section 12.3 some of the groups of interviews in this study reached saturation suggesting that sample sizes were more than adequate. The sample in this study is small and purposive rather than large and random. This means that power calculations are irrelevant and generalisation and prediction is impossible. Repertory grids do not require power calculations and therefore the sample size might rest uncomfortably in some experimental research quarters. What was done was entirely consistent with repertory grids and personal construct psychology.

Despite the fact that the sampling frame and size were in accordance with the research protocol adopted, there are limitations with the sample in this study:

- Because of the methods adopted, generalisations were not possible
- Some of the quantitative measures (VAS, KHQ) in the third patient group were not amenable to statistical analysis partially because the sample was underpowered for these tools
- The tools were not chosen to use alone – rather to help sort the qualitative sample and data into groups – satisfied/dissatisfied, cured/not cured etc. While this approach seemed appropriate it was not possible to make these dichotomies. The problem with defining success and cure was discussed in Sections 4.5, 4.6, 4.8, 13.4, 13.5 and 17.1. As yet, there are no other recognised methods any better at measuring cure and satisfaction

There were three groups of subjects in this study:

- Group 1 was a general group of women who had UI (of any aetiology)
- Group 2 had previous surgery for SUI
- Group 3 had already been put on the waiting list for USI surgery

These are three quite distinct groups with no equality, randomisation or comparison. The purpose was to get a general view of UI and its various treatments (Group 1). Group 2 then allowed the focus to narrow and concentrate on women who had previously experienced surgical treatment for UI. The third group was the only group who received an intervention during the course of the study, as described in Chapter 11. These women were recruited after being put forward for USI surgery. They underwent evaluation prior to surgery and again afterwards. This is the only group that may have leant itself to randomisation in some form. This would not, however, have fulfilled the aims of this study since they were not to evaluate a treatment. There were no between group comparisons in this study because the groups were not devised to be comparable. The way in which the groups were arranged may have led to bias since they were selected by being applicable to their description. This was not important as long as there was no attempt to compare the groups (since they were not comparable). However, control of bias is essential for objectivity in experimental research, but is of less significance in PCT.

The individuals included in this study were not necessarily representative of the whole female population with UI. They were all fluent in English and all had been attending a tertiary urogynaecology unit. Most of these women were still attending the

service at the time of the study and therefore were more likely to be unsatisfied with their management. This will therefore have biased the results towards negative outcomes and will not be representative of the whole population of women with UI and their treatment outcomes and experiences. This was in part addressed with the third patient group who were identified prior to USI surgery and a number of these women would have been expected to have a good outcome. The study of those with a negative outcome was not seen as a weakness since dissatisfaction is the main area of study. Even in the unbiased group, identified prior to surgery, it was the study of those who were dissatisfied that was desired. The aim of the study was not to examine those who were satisfied since this does not pose a management difficulty, rather to identify and address dissatisfaction and subjective reasons for subjective dissapointment.

18.1.4 Methods used in the study

The thesis has used a variety of research methods to obtain results relating to the aims and objectives of the studies. The investigation of areas not currently adequately addressed in the management of UI was the focus of interest. The study was careful not to predict the issues by making measures on predetermined scales (which has the limitation of ceilings or floors when things are absolute), rather to find out these issues de novo and in a manner relating to the individual. The lack of specific items to measure participants on may seem foreign to the quantitative researcher but the nature of the research question demands a wide range of answers to be accommodated. The study methods were primarily qualitative and exploratory which means that the tight experimental control demanded by hypothesis-testing

paradigms is neither appropriate nor necessary. They did, however, provide a richness of experiential data, essential to the nature of the project. They also afforded an opaque investigation into a sensitive subject. Rather than using the gold standard RCT research method more subjective methods were chosen. This means that results are not generalisable, and that no 'laws' of behaviour were elicited. Prediction is not possible and nor is objectivity. Because the measures taken were not objective they are not verifiable, however, the nature of the research question was a focus on in-depth, subjective experience, which the RCT cannot provide. PCT does not require generalisability and indeed, is anathema to its central tenants.

There are different types of design for experiments such as between-subject, within-subject and single-case[97]. An alternative quasi-experiment, which studies individuals in their natural setting and does not require randomisation, has a potentially useful role in understanding the effects of professional practices[97]. With subjective methods the researcher can interact with respondents to get close to what respondents think and experience. Subjectivity is also present in the choice of participants in qualitative studies[97]. One of the preferred methods is to select people whom researchers or their colleagues believe may be suitable for their studies by virtue of having knowledge or experience of the phenomena being investigated[97]. Data analysis may be considered subjective since other researchers may analyse the data differently and even obtain different results[97]. Conversely quantitative researchers are expected to adopt an objective stance and stand outside the phenomenon in order to study it[97]. This should make the findings free from bias and if the same process is followed by other researchers similar results should be obtained[97]. The stance of the quantitative

researcher is that they know something and are researching to prove it[97]. This makes objectivity undesirable in this study since the methodology and study design were chosen to allow the emergence of new things – it was exploratory in focus and purpose. The objective stance of the quantitative researcher also means that they do not get close enough to respondents to take a close look at the area of study and this is another reason why objective methods are not suitable in this study. While objectivity has the advantage of uniformity and consistency it also creates a distance between the researcher and the researched, which can result in a superficial understanding of the phenomenon. Qualitative researchers can, however, exploit the notion of subjectivity in order to collect useful data and therefore need to be rigorous in their approach[97].

The research plan incorporated a variety of data sources – a literature review, a focus group, repertory grids, qualitative interviews, KHQ, VAS and urodynamic studies. These methods are critiqued in detail in Section 6.11. This multimethod approach is common in the social sciences as different methods can complement each other[90]. The advantages of the multimethod approach are:

- To get a more detailed perspective on a particular aspect on some of the issues raised[90]
- One method can influence the structure and composition of an additional method[90]
- To compare different versions of similar documents – for example written and spoken documents[90]

- To verify the validity of information being collected by using more than one method[90]
- To allow for a change of direction in the project, especially if during the literature review it is found that one of the methods has already been used before for the same research or one of the methods is not gathering the information it was designed to collect[90]
- To allow qualitative and quantitative methods to be used in combination[90]
- A more holistic approach may be allowed to emerge[221]
- In-depth, qualitative methods can provide content validity for tools such as questionnaires whose reductionist approach may otherwise lack validity[221]

The advantage of mixing quantitative and qualitative methods is that it allows different aspects of the same phenomena to be studied. This triangulation is defined as the combination of two or more theories, data sources, methods or investigators in the study of a single phenomenon and there are six types of triangulation – theory, data, investigator, analysis, methods and multiple[221]. Drawbacks of the multimethod approach are that findings may be contradictory although this can actually enhance the researchers understanding of an area[221].

The use of repertory grids in this field was new and therefore part of the work involved a pilot phase of action research to design and refine the technique so that it was fit for purpose and useable (see Chapter 10). The repertory grid is part of PCP and is an opaque measure. The nature of UI means that it has long been a taboo subject and this has been demonstrated in previous qualitative studies[25-27;118]. With

direct open questioning about UI there is a risk that a woman may choose to hide certain aspects of her life with UI, through embarrassment or shame. If leading questions or questionnaires are used then women may feel restricted in their responses and a failure to create a full and truthful picture results. The beauty of the repertory grid is that the subject feels they are being asked to compare things (the elements) and in doing so give away the terms in which they see those things (the constructs). This is a highly appropriate, opaque method for studying an embarrassing condition such as UI. The pilot study allowed refinement of the technique to ensure that collected information was useful.

Some quantitative methodology was used in this study, namely the use of the KHQ and the VAS. These use predetermined questions that can be scored. The scores are then available for statistical manipulation. This study aimed to explore feelings, experiences and attitudes and therefore qualitative methods were more appropriate. The data rich results are arguably more difficult to handle and require detailed analysis and interpretation to provide meaningful conclusions. There are recognised techniques of analysing such data and thematic analysis was used in this study and was critiqued in full in Section 6.11[94].

Initially qualitative interviews were performed to see whether the repertory grids were capturing relevant information and to provide some background should it be required at a later stage. With practice the interviews became very full and data rich in themselves and the themes generated were included in the final results along with the results from repertory grids, the literature and the focus group (Chapter 15).

With qualitative methods there is a lack of conventional statistical analysis. With quantitative research statistical manipulation is usual to measure the effect of an intervention, the strength of an association or comparison between groups of comparable subjects. While some of the methods used, including the repertory grid, are amenable to some statistical analysis the meanings are much more important to the research aims. Some statistical analysis was presented in Chapter 14 and provided an overview of the work 'at a glance'. The whole meaning and depth of the study is really lost in this kind of representation and is better represented in the more lengthy narrative and thematic networks (found in Chapters 8, 9, 10, 11, 12, 13 and 15 and Appendices VI, VII, VIII, XI and XII).

Urodynamic studies were performed to provide an objective measure and because they are seen as the gold standard to help direct treatment – particularly surgery. The aim was to identify cured but dissatisfied patients. This was not possible due to a lack of consistency between outcome measures and this discordance is of great interest. It appears that current methods of evaluation are falling short of capturing patients' real experiences. It is very important in everyday clinical practice to recognise this. Urodynamic studies were critiqued in Section 6.11.

18.1.5 The findings

The findings, presented in Chapters 15, 16 and 17, suggest that there are issues that are not covered by current QoL measures and which therefore need incorporating into treatment plans. The study also provides guidelines for customising patient care

as discussed in Chapters 16 and 17. These approaches may make management of UI more effective both clinically and financially.

Chapter 15 combines all of the themes found in the literature review, focus group and interviews. It is an account from a wide range of sources and this increases the content validity of any future tool produced. The analysis is not concerned with counting frequencies of themes or numbers but it is concerned with providing a full and detailed account.

18.1.6 The significance of the study

The original nature of this work, both in its aims and methodologies, was emphasised throughout the thesis. The overarching intention of this work, to improve patient satisfaction, was clearly made. Some of the findings overlapped with previously performed work and this offered a confirmatory element to this study and may corroborate some existing measurement techniques. A patient-centred focus underpinned the whole study. The concept of using the results as the first stage to help to plan treatment is original and novel. Previous studies either have looked at the impact of treatment on QoL or whether or not goals were achieved following treatment. Broadly speaking this identifies which is the best treatment (a 'one size fits all' approach). This does not inform clinicians which treatment is most beneficial for each individual patient and once an evaluation of outcome is made any harm has already occurred. The research programme aims, ultimately, to prevent 'harm' and to avoid 'lack of benefit', wasteful treatments by tailoring treatment plans to individuals. The challenges in defining cure and measuring outcome are discussed throughout

the thesis. The understanding of this will undoubtedly change significantly over the coming years. Many of these changes are being driven by the recognition of many of the theories and observations generated by work like this thesis.

18.2 Implications for future research and investigations

18.2.1 Methodological implications

The usefulness of the repertory grid in this sort of work is clearly illustrated throughout this study. Use of the repertory grid would be recommended when exploring similar topics in the future particularly where an in-depth exploratory method is desired for topics that are highly personal or associated with embarrassment, as the measure is opaque. Thematic analysis had been appropriate in this study. The use of a pilot group to refine methodology was very important in the development and success of the repertory grid and qualitative interviews. Further piloting may have improved the usefulness of data collected in later cohorts of the study and certainly in future work piloting would be useful.

18.2.2 Follow-on research

The development of a treatment-planning tool would build on the foundations laid by this study. The methods for that phase of work would be very different to this study. Larger samples of subjects would be required and information given to them is much more likely to be standardised. A questionnaire can be generated using this study to identify all of the issues, concerns and experiences relevant to the population under study. After piloting and testing the questionnaire can be given to a large sample at

the start of their treatment journey. The questionnaire can be repeated, or a modified one used, after various interventions. It may be possible to perform regression analysis to see if pre-treatment factors can be linked to success and satisfaction outcomes. The overall aim is to be able to predict who will benefit from which treatments. The key issues that were found that were not covered by conventional disease-specific QoL measures need to be embedded in a properly constructed psychometric measure, which can be used as a risk assessment tool and as an outcome measure in itself. The data from this would inform treatment-planning. This is outside the scope of this study, but the findings from this work provide the construct and content validity for the next stage – the development of the questionnaire.

18.2.3 Parallel research

This study has clearly identified areas where current treatment falls short (Chapter 16). Studies could be set up to see if any of the suggestions are of benefit. The only problem of looking at these separately is patient selection. Studied alone it may not be possible to select the most beneficial measures for individual patients without the work recommended for developing the overall treatment-planning tool. Some examples follow:

- Measure people's satisfaction with information surrounding surgery. Then an improved information-giving regimen could be developed, introduced and re-evaluated

- Screen for psychological or psychiatric conditions prior to undergoing surgery. Psychiatric or psychological conditions could be addressed. The subjects could then be re-evaluated for surgery to see how many of them still require it
- It may be possible to better manage people's expectations of UI treatments. This may help them to adapt post-treatment to their new state. Interventions in this regard may need to be applied prior to treatment and possibly after (or even during) treatment to manage expectations

This study has also highlighted the difficulty of defining cure and evaluating outcome. Despite numerous measures, some of which are in use clinically, some of which are objective or subjective, it was not possible to divide our population into cured and not cured. This leads us to ask the question 'what is cure?' and what are current success rates for particular interventions based on? There may be a need for standardisation of outcomes or subdivision of outcomes to being more specific. This study has shown that people are sometime happy they had an operation that has not worked for them at all, just because they did something to try to help themselves. These factors are consistent with evidence from locus of control studies, self efficacy and stress reduction[222] . They are not usually taken into consideration and perhaps they should be in future outcome work.

Allied specialities such as urology may benefit from similar work and their male population may well suffer similar experiences. Other surgical specialities may benefit from studying experience, expectation and outcome measures used.

18.2.4 Dissemination of findings

Throughout the period of study various presentations and publications have been made and these are outlined at the start of each relevant chapter and in Appendix XIII. International presentations have been made at specialist multidisciplinary meetings so that the work is already known in the field. This thesis will be available on the Universities e-Library so that it can be accessed by future researchers and clinicians wishing to read details of the study undertaken. The study will be submitted to peer review journals so that it will be available to clinicians and researchers in the field of urogynaecology. It may be of interest in the nursing and psychology literature and this avenue will also be explored. Follow-on work will continue and the findings of this study will form the basis for future work. Ongoing dissemination and development will therefore occur via future researchers. Most importantly this thesis has prepared the way for future work looking at trying to individualise patient management plans to try and optimise outcomes for patients. It has added to the debate of ‘what is a good outcome?’ and ‘how should outcomes be assessed?’ It has helped in recognising that after 20 years of reductionist theory that a single patient measure may give the best global outcome measure, but that expansion on patient centred care helps plan this. The future development of instruments that help evaluate this will inevitably contribute to this embryonic area of care within urogynaecology and pelvic floor medicine.

Appendix I

RESEARCH PROPOSAL FOR DOCTORATE OF MEDICINE (MD)

Title Psychological aspects of women suffering urinary incontinence and their expectations of treatment

Objectives

1. To find out what is known about the association between urinary problems and psychological problems

2 To find out what is known about the effectiveness of psychological interventions to augment treatment for patients suffering urinary incontinence

3 To find out what patients' experiences are of urinary incontinence and its treatment

4 To find out what aspects of urinary incontinence are not altered by current treatment

5 To find out what patients expectations of incontinence surgery are

6 To find out why some patients who are "cured" of incontinence still do not seem to be satisfied with their outcome.

7 To identify themes with which to develop a screening tool to apply to incontinent patients to determine whether they need additional psychological support or educational measures and to predict whether or not they are likely to benefit from different incontinence treatments.

Background review

1. Incidence and aetiology of the problem

The prevalence of urinary incontinence varies from paper to paper due to differences in populations, definitions and under-reporting of the condition due to embarrassment and other reasons. The department of health in their document 'good practice in continence services' suggest that the problem exists in 5 to 7% of women aged 15-44years, 8 to 14% aged 45-64 years and 10 to 20% in women who are 65years and over. Figures are higher for those in institutions with 2/3 in nursing homes suffering urinary incontinence.
For some women it may be a mild occasional event from which they remain unaffected whilst for others it is an embarrassing, unhygienic and socially isolating problem affecting many domains of their lives.
There are various different types and causes of urinary incontinence but the most common types are stress incontinence, overactive bladder and mixed incontinence.
Stress incontinence is due to changes in the anatomy and structure of pelvic floor muscles, connective tissue and/or innervaton. It may be related to but not exclusive to those who have been through pregnancy and childbirth. Overactive bladder occurs when the detrusor muscle

contracts at an inappropriate time resulting in urinary urgency which can result in incontinence. A combination of the two types (known as mixed incontinence) leads to diagnostic and therapeutic challenges.

2. Current approaches to treatment

Women who present complaining of urinary incontinence require careful evaluation in the form of history taking, clinical examination and investigation as appropriate. Treatment is directed by the information gained from this diagnostic process. Current treatment options include advice on fluid intake, pelvic floor exercises, bladder retraining, medication and surgery. These are delivered by a wide range of healthcare providers in primary, secondary and tertiary care including continence advisers, general practitioners, physiotherapists, continence nurse practitioners, gynaecologists, urologists and urogynaecologists. Those resistant to treatment will need containment measures.

3. Challenges in current management.

The methods by which continence treatments are evaluated vary. One approach is to objectively measure the amount of incontinence by using physical tests such as pad tests or formal urodynamic investigation. This method will demonstrate whether or not a woman leaks urine but does not evaluate whether or not she has a better life as a result of treatment. Quality of life evaluation is designed to measure improvement or satisfaction. There have been various tools used to assess quality of life- both in general and in relation to urinary incontinence.

Combinations of treatment are often used for various types of urinary incontinence and it can be difficult to distinguish which part of the treatment has conferred more therapeutic advantage. For example women with an overactive bladder are likely to receive advice on their fluid intake and toileting and may also be commenced on oral medication. A woman with mixed incontinence may have all these treatments and physiotherapy in addition.

Patient selection for various treatments is also important. Stress incontinence surgery performed on women who also have urge incontinence is likely to lead to an unsatisfactory outcome even if her stress incontinence is cured. Urge incontinence can actually be exacerbated or commence following pelvic surgery and these pitfalls are well recognised.

Current continence surgery in those with stress incontinence is felt to have a success rate of around 80% although lower success rates have also been suggested, possibly reflecting the debate over what constitutes a cure. Physiotherapy is thought to be sufficient treatment for around 50% of women with stress incontinence.

4. The extent of the problem of clinical success versus psychological dissatisfaction with outcome

Some women may not change their behaviour and habits even if their treatment appears to be successful or has conferred a subjective improvement. For example some women who no longer leak urine may still wear a pad ‘just in case’ or are still afraid to stray away from where

they know there is a toilet. Their lives may not be significantly improved even though they have been cured.

Urinary incontinence has behavioural elements in both its development and treatment. Biofeedback and bladder retraining are in general use and both are based on psychological techniques. These are directed towards particular incontinence problems and do not deal directly with the psychological conditions found to be so prevalent in an incontinent population. Response to treatment for incontinence may also have psychological elements but this has not been explored.

5. Literature on the research conducted on the interface between psychology and medicine in this area

There has long been known a link between urination, urinary dysfunction and the psyche. In 1941 Karl Menninger identified certain erotic and aggressive values in urination which were present in some of his patients. In 1949 Straub demonstrated changes in intravesical pressure on cystometry during emotional or stressful conversations. In 1979 Molinski suggested that masked depression was present in a number of gynaecological complaints including urinary incontinence.

A background literature review has shown increased hysteria, hypochondriasis, schizophrenia, anxiety, somatisation, neuroticism, obsessionality, irritability, inner anger and depression in patients with urinary complaints compared to the normal population. Some studies have shown the prevalence of some conditions to be as high as in psychiatric inpatients. These conditions are not routinely sought or treated in the current management of urinary incontinence. It is possible that co-existing psychological morbidity may affect different patients' responses to certain treatments and that addressing their psychological problems may improve their overall outcome.

In 1987 Macauley randomly allocated patients with overactive bladders or sensory urgency to one of three treatments – psychotherapy, bladder training and medication. There was a statistically significant improvement in nocturia, urgency and incontinence in the psychotherapy group.

In 1982 Freeman performed hypnosis on 50 incontinent women with proven overactive bladders. Three months later 44 of them had a stable bladder on cystometry translating into an 88% cure rate. This is as good as or even better than existing conventional incontinence treatments but is not in general use.

Due to the low number of studies involved in psychological interventions for incontinence and the lack of control groups it is not possible to say that these should be adopted in clinical practice.

The theory of personal constructs suggests that individuals perceive the world in a highly personal way and people actively try to make sense of the world so that they can predict events and respond appropriately. This will influence how people do or do not adapt to changes in their life such as incontinence or undergoing surgery. The technique of repertory grid analysis attempts to establish how any given individual perceives her own world.

6. Project aims

This project aims to identify possible common factors in women who experience dissatisfaction despite good surgical outcomes and find out what aspects are left untreated or unresolved by current incontinence treatment. This would then form the basis of a screening tool. This is the preliminary stage of what is expected to be a much larger project in this field.

7. Pilot study

I have undertaken a pilot series of six preliminary interviews amongst urogynaecology inpatients and outpatients to check the feasibility of the study and its methods
A semi-structured interview style called the repertory grid technique is being used. This allows the subjects to describe events and experiences in their own terms in line with personal construct theories. Through the course of the repertory grid technique, interviewed subjects will assign scores to various aspects of their expectations and experiences. This is a very individual and in depth interview process and is not amenable to large scale experimental design. A small number of interviews generate a lot of qualitative and quantitative data. Six preliminary interviews have already been performed on women with urogynaecology problems using the repertory grid technique. These have been followed by detailed interviews regarding patients' experiences of incontinence and their expectations and experiences of treatment. These interviews have allowed development of the technique of performing repertory grids.

Already obvious themes of hygienic concerns, self-confidence issues and disappointment with healthcare have emerged and these issues need to be explored further to see if they are commonly held issues amongst incontinent women.

Research methods

1. To find out what is known about the association between urinary problems and psychological problems

A basic literature search has been performed on Medline and psychinfo electronic databases. Search terms including 'incontinence' and 'psychological tests' have been used. These papers have been hand searched for other relevant references which have also been obtained. This search will be developed to obtain further papers of relevance.

2. To find out what is known about the effectiveness of psychological interventions as a treatment for patients suffering urinary incontinence

To be obtained via literature searches and review of relevant papers as for 1.

3. To find out what patients' experiences are of urinary incontinence and its treatment

This will be obtained by performing semi-structured interviews with three groups of patients.

Group 1- general complex patients identified from outpatient urogynaecology clinics or inpatients undergoing bladder investigation or retraining. These patients will undergo a repertory grid semi structured interview. The patients will be selected from those attending the urogynaecology outpatient services in Birmingham Women's Hospital and patients being admitted for surgery or bladder retraining (20 cases).

Group 2- patients who have undergone surgery for stress incontinence. They will have semi structured repertory grid interviews performed. They will also be given a form to assess their subjective success of surgery using visual analogue scales and they will complete a form asking which situations are more and less affected by their incontinence
(20 cases).

Group 3- patients who are due to undergo surgery for stress incontinence. They will be seen preoperatively and will have urodynamics, repertory grid semi-structured interview and complete a questionnaire regarding quality of life and pad usage.
Post operatively 6 weeks to 6months, they will have a pad test or urodynamics, repertory grid semi-structured interview, questionnaire regarding quality of life and pad usage (40 cases).

All patients participating will have written consent. An ethics application to COREC is currently being undertaken.

4. To find out what aspects of urinary incontinence are not altered by current treatment

As for 3.

5. To find out what patients expectations of incontinence surgery are

As for 3.

6. To find out why some patients who are cured of incontinence still do not seem to be satisfied with their outcome.

As for 3.
The third patient group (pre-operative/post-operative) will have an objective measurement of objective success (urodynamics/pad test). Those patients who are dissatisfied but are objectively cured will provide valuable information that should identify their points of dissatisfaction. Themes will also be drawn from the interviews with both the complex general group and the postoperative groups.

7. To identify themes with which to develop a screening tool to apply to incontinent patients to determine whether they need additional psychological support or educational measures and to predict whether or not they are likely to benefit from different incontinence treatments.

The themes identified can be used to form the basis of a questionnaire to pose to people considering surgery.

<u>How the data will be analysed, presented and interpreted</u>

Each repertory grid can be analysed individually to ascertain certain associations. There are computerised packages available to analyse repertory grids eg INGRID.
The grids can also undergo semantic analysis using Roget's thesaurus to identify recurring themes.
All the grids can be analysed together to draw out themes of the experience and concerns of incontinent people.
Groups of interview grids will also be compared. Satisfied patients grids and dissatisfied patients grids can be compared. Grids will be compared between patients who are dissatisfied and satisfied who are objectively cured.

Expected outcome

It will establish what aspects of incontinence are important to patients, what they expect from surgical treatment and whether or not these expectations are being met by surgical treatment. It will identify areas that are not met by current management of incontinence.

Value of the research

It is anticipated that this research will form the basis for a screening tool providing construct and content validity. If patients' expectations are not met then the aspects that are unresolved should be addressed in preoperative counselling. Aspects of incontinence which may be manageable may be uncovered, in which case these aspects can be addressed.
It is anticipated that this work will be repeated for other modes of incontinence treatment such as medical and behavioural therapies. It is anticipated that a screening tool will be developed to apply to patients before treatment to determine which course of treatment they are most likely to benefit from.
If psychological features are uncovered then there may be a role for increased psychological input into patients presenting with urinary incontinence

If time permits

Other centres may be asked to participate to allow sample sizes to be expanded.

Summary plan for research

Literature review of psychological aspects of incontinence.

Literature review of the use and technique of the repertory grid technique.

Perform repertory grids and semi structured interviews on complex general cases (target 20 cases).

Perform a repertory grid semi structured interview, subjective assessment of success using visual analogue scales and situations more and less affected by incontinence on post-operative cases (target 20 cases).

Perform a repertory grid, pad usage questionnaire, quality of life questionnaire and urodynamics preoperatively. Post operatively perform a repertory grid, urodynamics, pad usage and quality of life questionnaire (target 40 cases).

Analysis of individual grids and comparisons between groups of grids.

Draw together results and conclusions.

Appendix II

CONSENT FOR INTERVIEW

***Hospital number*_____**

I _____ of _____
(name) *(address)*
_____ agree to an

interview with _____ who is a_____
(name of interviewer)
_____.
(job title)

I understand that this is for the purpose of research into psychological aspects of urinary incontinence.

I understand that this is voluntary and I may end the interview at any time by request. I do not have to answer any questions that I do not wish to answer.

This interview process does not form part of my current healthcare. If factors are discovered that may be useful in my current care then this may be passed on to the people responsible for my care with my permission.

I understand that the results of the interview may appear as part of a thesis and/or publication but that my name will not be disclosed.

The interview may be recorded by notetaking, audiotape or videotape and I have been informed of which method will be used.

I have had an opportunity to ask questions prior to starting the interview and I am happy to proceed with the interview.

SIGNED_____ date _____
Print name _____

Appendix III

Birmingham Women's Health Care NHS
NHS Trust

~ Psychological aspects of urinary incontinence ~
PATIENT INFORMATION SHEET & CONSENT FORM

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?
Accidental leakage of urine (urinary incontinence) is an important condition and can affect people's lives in many ways. This study aims to find out more about women's experiences of urinary incontinence and its treatments. It is hoped that this will improve patient care.

Why have I been chosen?
You have been chosen as someone who may be able to provide valuable information and you will fall into one of the three groups below. It is hoped that approximately 80 women will take part in this study.

Group 1- women with general continence problems. Some of whom will have been through a variety of treatments.
Group 2- women who have previously undergone continence surgery.
Group 3- women who are due to undergo continence surgery in the future.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
This depends on which category you fall into

Group 1- if you have general continence problems. You will be asked to take part in an interview with the researcher. This will be in three parts:
-the researcher will ask you some questions and fill in a form.
-you will be interviewed by the researcher.
-you will be asked for a short list of activities affected by incontinence.
The time taken varies between individuals. It usually takes somewhere between 30 and 90 minutes.

Group 2- if you have already had an operation for urinary incontinence. You will be asked to rate how successful you think the operation has been. You will then be asked to participate as per group 1.

Group 3- if you are due to undergo continence surgery in the future. You will be asked to undergo an interview as per group 1. You will also be asked to complete a questionnaire regarding quality of life and pad useage. Between 6 weeks and 6 months after your operation you will attend the hospital and have these questionnaires and interview repeated. In addition you will be asked to rate how successful

you think that the operation has been and a test (called urodynamics) will be performed to see how effective your bladder operation has been. The test (urodynamics) is identical to the test you had before deciding to have your operation. An alternative pad test is available if you do not want to have the urodynamics test (ask a member of staff if you want more details about these tests).

What do I have to do?
If you wish to participate in the study then you will be asked to participate in the events described above. This will not affect your treatment or lifestyle in anyway.

What are the possible benefits of taking part?
This study is not intended to change your management. However, some women may feel better after talking things through in detail as there are no time restrictions for interviews. If factors are found which can be addressed then these factors can be highlighted to you nurse/doctor/GP for further attention if you wish.

If you are in group 3 then you will have bladder tests after your operation (this does not routinely happen if you are not in this study). If other bladder problems are uncovered by bladder tests then this can be addressed with further treatment if needed.

The information we get from this study may help us to treat future patients better.

What if something goes wrong?
If something is discovered which requires attention you may be referred to an appropriate professional, either directly or via your GP. If you wish to speak with a nurses or another doctor in the urogynaecology department then this can be arranged for you. If have any concerns about any aspect of the way you have been approached or treated during the course of this study you can contact the Patient Advice & Liaison Service (PALS) on 0121 6272747.

Will my taking part in this study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it. Your GP may be informed that you are participating in this study and information will only be passed on to your hospital nurse/doctor or GP with your permission.

What will happen to the results of the research study?
The results of the study will be written into an academic thesis and may be published in journals or presented at meetings. You will not be identified in any report/publication.

Who is organising and funding the research?
The research is organised by Dr Katharine Robb and Mr P Toozs-Hobson in Birmingham Women's hospital. They are employed by Birmingham Women's Health Care NHS Trust and do not receive additional payment for including you in this study.

Who has reviewed the study?
The study has been reviewed by specialists in continence and psychology. It has also been reviewed by the Research and Development department of Birmingham Women's Healthcare NHS Trust.

Contact for Further Information
Dr Katharine Robb – research fellow in urogynaecology.
Ward 6 – urogynaecology, level 3, birmingham womens Hospital.Telephone 0121 6272756

Thank you for taking part in this study
You will be given a copy of the information sheet and a signed consent form to keep.

July 2005 version 5.

Birmingham Women's Health Care NHS

NHS Trust

Centre : Birmingham Women's Hospital
Study: Psychological Aspects of Urinary Incontinence
Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Psychological Aspects of Urinary Incontinence

Name of Researcher: Dr Katharine H Robb

Patient identification label

Please initial box

1. I confirm that I have read and understand the information sheet dated Jan 05 (version 3) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, ☐ without giving any reason, without my medical care or legal rights being affected.
3. I understand that sections of any of my medical notes may be looked at by responsible ☐ individuals from Birmingham Women's Hospital or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.
4. I agree to take part in the above study. ☐

_____	_____	_____
Name of Patient	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 for patient; 1 for researcher; 1 to be kept with hospital notes

July 2005 version 5

Appendix IV

PREOPERATIVE INTERVIEW SCHEDULE

Consent completed ☐ date…….

Repertory grid

elements→ bipolar constructs ↓	Me- before the bladder problems started	Me – when my incontinence was at its worst	How I expect to be after surgery	How I hope to be after surgery	Me now	Something that I would like to do that I can not do now because of the incontinence
1= 7=	O		O		O	
1= 7=	O	O	O			
1= 7=		O		O		O
1= 7=			O		O	O
1= 7=	O			O		O
1= 7=		O		O	O	

Tell me three things you really enjoy or like
Tell me three things you dislike or hate

elements→ bipolar constructs ↓						
1= 7=	O		O		O	
1= 7=	O	O	O			
1= 7=		O		O		O
1= 7=			O		O	O
1= 7=	O			O		O
1= 7=		O		O	O	

Situations affected by incontinence

Please list five situations were your incontinence causes you the most difficulties

1.

2.

3.

4.

5.

Please list five situations were your incontinence is less of a problem to you

1.

2.

3.

4.

5.

Do you wear pads or any extra protection? YES / NO

If yes, what sort of pads do you use?

How many a day do you use?

Why do you wear them?

Interview

Tell me about your bladder problems from the start

Pre-operative Urodynamics results

Date of urodynamic test ……

Was stress incontinence demonstrated? Yes / no / comment……

Was there detrusor overactivity on filling? Yes / no / comment……...

Was there provoked detrusor overactivity? Yes / no / comment……...

Was there any voiding dysfunction of flow or residual? Yes / no / comment ……..

Additional comments

POSTOPERATIVE VISIT

TIME SINCE OPERATION…….
OPERATION PERFORMED……
Date of operation…….

Post-operative Urodynamics results

Date of urodynamic test ……

Was stress incontinence demonstrated? Yes / no / comment……

Was there detrusor overactivity on filling? Yes / no / comment……...

Was there provoked detrusor overactivity? Yes / no / comment……...

Was there any voiding dysfunction of flow or residual? Yes / no / comment ……..

Additional comments

Assessment of subjective success of surgery for stress incontinence

In order to evaluate how successful you feel your surgery has been please answer the following questions.

Place a vertical line along the ruled horizontal line at the point you feel represents your answer

Question 1)
Mark below on a scale of 0 to 10 how successful do you feel your operation has been?
O = not successful
10= completely successful

_____
0 10

Question 2)
Mark below on a scale of 0 to 10 how satisfied you are with the out come of your operation
0= not satisfied at all
10= completely satisfied

_____
0 10

Question 3)
Mark below on a scale of 0 to 10 how happy you feel at the moment
0= very unhappy
10= very happy

_____
0 10

Question 4)
Mark below on a scale of 0 to 10 how relaxed you feel at the moment
0= very relaxed
10= very tense

_____
0 10

Question 5)
Mark below on a scale of 0 to 10 how much urinary leakage you suffer now
0=leak all the time
10= never leak

_____
0 10

Repertory grid

elements→ bipolar constructs ↓	Me- before the bladder problems started	Me – when my incontinence was at its worst	How I expected to be after surgery	How I hoped to be after surgery	Me now, after I have had the surgery	Something that I can do now that I could not do before the surgery because of the incontinence
1= 7=	O		O		O	
1= 7=	O	O	O			
1= 7=		O		O		O
1= 7=			O		O	O
1= 7=	O			O		O
1=		O		O	O	

7=						

Tell me three things you really enjoy or like
Tell me three things you dislike or hate

elements→ bipolar constructs ↓						
1= 7=	O		O		O	
1= 7=	O	O	O			
1= 7=		O		O		O
1= 7=			O		O	O
1= 7=	O			O		O
1= 7=		O		O	O	

Situations affected by incontinence

Please list five situations were your incontinence causes you/caused you the most difficulties

1.

2.

3.

4.

5.

Please list five situations were your incontinence is less of a problem to you

1.

2.

3.

4.

5.

Do you wear pads or any extra protection? YES / NO

If yes, what sort of pads do you use?

How many a day do you use?

Why do you wear them?

Interview

Tell me what you think about how your operation went and how thing have been since it

Appendix V

KINGS HEALTH QUESTIONNAIRE

V.I Calculation of scores

V.II The Questionnaire

V.I Calculation of scores

Qu in the formulae below is short for questions and refers to the score for each question in the questionnaire in V.II. To Calculate Scores for the following domains:

1. General Health perceptions

Score = (Score to Qu1 - 1)/4) x 100

2. Incontinence Impact

Score = (Score to Qu 2 - 1)/3) x 100

3. Role Limitations

Score = (Scores to Qu 3a+3b) -2) /6) x 100

4. Physical limitations

Score = (Score to Qu 4a+4b) - 2) /6) x 100

5. Social limitations

Score = (Score to Qu 4c+4d+5c) - 3) /9) x 100 **

** If score to Qu 5c >= 1, If 0 then.-2) / 6) x 100

6. Personal Relationships

Score = (Score to Qu5a+5b) - 2) /6) x 100 ***

** If score to Qu 5a+5b >= 2,

If Qu 5a+5b = 1;-1) /3) x 100
If Qu 5a+5b = 0;treat as missing value (Not applicable)

7. Emotions

Score = (Score to Qu 6a+6b+6c) - 3) /9) x 100

8. Sleep / Energy

Score = (Score to Qu 7a+7b) -2) /6) x 100

9. Severity Measures

Score = (Score to Qu 8a+8b+8c+8d+8e) - 5) /15) x 100

The response to each question is scored as follows:

1. How would you describe your health at present ?

Very good	1
Good	2
Fair	3
Poor	4
Very poor	5

2. How much do you think your bladder problem affects your life?

Not at all	1
A little	2
Moderately	3
A lot	4

3a. To what extent does your bladder problem affect your household tasks (eg cleaning, shopping etc)?
3b. Does your bladder problem affect your job, or your normal daily activities outside the home?
4a. Does your bladder problem affect your physical activities (eg going for a walk, run, sport, gym etc)?
4b. Does your bladder problem affect your ability to travel?
4c. Does your bladder problem restrict your social life?
4d. Does your bladder problem limit your ability to see / visit friends?

Not at all	1
Slightly	2
Moderately	3
A lot	4

5a. Does your bladder problem affect your relationship with your partner?
5b. Does your bladder problem affect your sex life?
5c. Does your bladder problem affect your family life?

Not applicable	0
Not at all	1
Slightly	2
Moderately	3
A lot	4

6a. Does your bladder problem make you feel depressed?
6b. Does your bladder problem make you feel anxious or nervous?
6c. Does your bladder problem make you feel bad about yourself?

Not at all	1
Slightly	2
Moderately	3
Very much	4

7a. Does your bladder problem affect your sleep?
7b. Do you feel worn out or tired?

Do you do any of the following; if so how much?

8a - Wear pads to keep dry?
8b - Be careful how much fluid you drink?
8c - Change your underclothes when they get wet?
8d - Worry in case you smell?
8e - Get embarrassed because of your bladder problem?

Never	1
Sometimes	2
Often	3
All the time	4

V.II The questionnaire

See overleaf

King's Health Questionnaire Subject No

1. How would you describe your health at present Choose one answer

Very Good	Good	Fair	Poor	Very Poor
□	□	□	□	□

2. How much do you think your bladder problem affects your life? Choose one answer

Not at all	A little	Moderately	A lot
□	□	□	□

Below are some daily activities that can be affected by bladder problems. How much does your bladder problem affect you?

We would like you to answer every question. Simply choose the answer that best applies to you.

ROLE LIMITATIONS	Not at all	Slightly	Moderately	A lot
3. To what extent does your bladder affect your household tasks(e.g. cleaning,shopping , DIY, etc…)?	□	□	□	□
4. Does your bladder problem affect your job, or your normal daily activities outside the home?	□	□	□	□

PHYSICAL /SOCIAL LIMITATIONS	Not at all	Slightly	Moderately	A lot
5. Does your bladder problem affect your physical activities (e.g. going for a walk, run, sport,gym,etc) ?	☐	☐	☐	☐
6.Does your bladder problem affect your ability to travel?	☐	☐	☐	☐
7.Does your bladder problem limit your social life?	☐	☐	☐	☐
8. Does your bladder problem limit your ability to see/visit friends?	☐	☐	☐	☐

PERSONAL RELATIONSHIP	N/A	NOT at all	Slightly	Moderately	A Lot
9. Does your bladder problem affect your relationship with your partner?	☐	☐	☐	☐	☐
10. Does your bladder problem affect your sex life?	☐	☐	☐	☐	☐
11. Does your bladder problem affect your family life?	☐	☐	☐	☐	☐

EMOTIONS	Not at all	Slightly	Moderately	Very Much
12. Does your bladder problem make you feel depressed?	☐	☐	☐	☐
13. Does your bladder problem make you feel anxious?	☐	☐	☐	☐
14.Does your bladder problem make you feel bad about yourself?	☐	☐	☐	☐

SLEEP/ENERGY	Never	Sometimes	Often	All the time
15.Does your bladder problem affect your sleep?	☐	☐	☐	☐
16. Do you feel worn out/tired?	☐	☐	☐	☐

DO YOU DO ANY OF THE FOLLOWING? If so how much?

	Never	Sometimes	Often	All the Time
17. Wear pads to keep dry?	☐	☐	☐	☐
18. Be careful how much fluid you drink?	☐	☐	☐	☐
19.Change your underclothes when they get wet?	☐	☐	☐	☐
20. Worry in case you smell?	☐	☐	☐	☐
21. Get embarrassed because of your bladder problem?	☐	☐	☐	☐

THANK YOU . NOW CHECK THAT YOU HAVE ANSWERED ALL THE QUESTIONS

Appendix VI

QUALITATIVE INTERVIEWS COMBINED THEMATIC ANALYSES (GROUP 1)

The global themes are:

- Symptoms
- Trigger for presentation
- Cause of bladder problems
- Treatments
- Staff
- Urodynamics
- Trials
- Impact of bladder
- Other people
- Coping mechanisms
- Emotional responses
- Normality
- Expectations
- The future
- Concerns

The entire thematic network is described below.

- **Symptoms**

Many symptoms were described by participants. Some pertain to OAB, some to SUI and some describe secondary effects of symptoms or leakage in general. Some subjects also feel that they have symptoms arising from other conditions, which are equal to or worse than their bladder symptoms. OAB symptoms mentioned included frequency, urgency, leakage and a sensitive feeling. SUI symptoms included leakage with activity, coughing, sneezing and when lifting children.

Wetness and Leakage in general was described '*I remember it running down my legs*' and the experience of wearing and having to change wet pads was described. One woman felt that she leaks when distracted such as at work or when pulling her pants down after a shower. Incomplete emptying occurred for one participant who feels that when your mind is on other things you don't always think of the toilet.

A participant, whose complaints were frequency and leakage, said that her symptoms were worse in the daytime initially but later became a problem at night. She also had difficulty in remembering the stages of her problem and relates this to not working and consequently having no time markers as points of reference.

Other symptoms mentioned are leakage with sex, nocturia, discomfort at night and unpleasant, uncomfortable bladder infections. One woman describes an ammonia type smell. Secondary effects included feeling uncomfortable at night and consequent tiredness the following day.

One woman felt that initially her problem was controllable and not severe. Nocturia was her initial complaint along with a bowel complaint. Several other participants also had concordant bowel complaints. One participant has a bowel problem that she describes as uncomfortable and unpleasant and her bladder became secondary to bowel problems. Another woman also had problems with diverticular disease and described pain in her left side with this. A further participant had to assist her bowels to open.

Symptoms and conditions apparently unrelated to the bladder were mentioned in the interviews. These included knee problems, heavy periods, varicose veins, diabetes, cancer, hypertension, hypercholesterolaemia, rheumatoid arthritis, circulation problems, groin pain, swollen ankles, abdominal pain, eye problems and back problems with loss of height. One woman was diagnosed with bacterial vaginosis and had difficulty accepting the diagnosis.

One woman's problems started with pain and leakage. She also complains of urgency and changing her knickers twice a day. She also gets a dragging pain, which goes right up her when she lifts objects or passes water. Other complaints include feeling uncomfortable with right-sided abdominal pain and leg pain, itching 'inside and out' and a weakness when passing urine.

- **Trigger for presentation**

One participant presented because she was fed up. Another came because '*the grandchildren joke and make comments*'. A further participant consulted her GP after

noticing a smell. Doing pelvic floor exercises made one woman more aware of her physical structure and that something was wrong. When she went to see her GP about a bowel problem she was asked about her bladder.

- **Cause of bladder problems**

Women often held beliefs about what had started their bladder problems. The most common beliefs seemed to be that childbirth was at least partially responsible. Causes stated included a forceps delivery causing internal damage, childbirth combined with age, pregnancies too close together combined with being overweight, difficult childbirth combined with a hysterectomy, bad tears at childbirth combined with multiple operations, bladder damage during a hysterectomy, a repair operation. Another woman started to notice a smell after childbirth.

Another women theorised that because of her back problems she had lost height and the lack of space for her bladder was resulting in her bladder problems. Some women felt that their bladder problems were related to emotion. One woman felt her bladder problems were due to infections, which caused her to loose blood. Recognition that bladder and bowel problems may be interconnected was realised by one subject but she also stated that she does not understand why the bladder problems happen. One woman thought that there was something pushing on her bladder making her need to go to the toilet. She also thought that her bowel management (increasing her fluid intake) makes her bladder worse. One participant wonders if her bladder and/or prolapse is responsible for her backache or whether it is wear and tear. A suprapubic catheter was blamed for tummy swelling and previous

surgery for bowel problems. One woman felt that she did not use her brain enough at work or in life in general and consequently did not have a lot to take her mind off her bladder. Another woman was worried in case there was an underlying medical cause such as a malfunctioning kidney.

- **Treatments**

There were wide ranging views and experiences of treatments. There were both negative and positive comments. One woman said that her GP had tried things that made no difference. One woman took ownership for her treatment saying '*trying my best now'*.

General advice about food and drink was mentioned by one woman who was told not to drink alcohol, which was not a problem. She was also told not to eat fruit but she says it is about a third of her diet and she really like fruit. Another woman says she was given advice at urodynamics but does not feel that she can defeat the problem at a practical level. She did find switching from coffee to tea beneficial. Another woman felt that fluid advice was the most useful thing. One woman initially treated her constipation.

Physiotherapy was considered a waste of time by one participant while just ineffective by another. A further participant cannot remember doing pelvic floor exercises while several felt that physiotherapy was of no benefit. One woman admitted to not doing pelvic floor exercises wholeheartedly because they did not work

before. One woman recalls how the devices fell out during physiotherapy and she found this humiliating. Another felt physiotherapy was difficult when they showed her. One of the participant's daughters are physiotherapists but she feels that her muscles are tight and the exercises did not help. Another woman said that she thought that pelvic floor exercises were '*okay*'. One woman found that through doing pelvic floor exercises she became more aware of her physical structure and that something was wrong. Another said that she could not manage *'the pelvic floor thing'* but does pelvic floor exercises when she can. Toning tables were used by one participant to tone her body and she was told it could '*help the pelvic muscles go tighter too'*.

Tablets were mentioned during many interviews. Most were anticholinergics but other tablets were also mentioned. Trospium was felt to be no help for one participant. Another women felt that tablets had side effects. Drug reactions were experienced by one woman who still says she prefers drugs to surgery. Negative things attributed to tablets included rash, diarrhoea, thirst, weight loss and a chest infection. One participant felt that the tablets helped and she used them if she was going somewhere. She was given something else but is not sure what. One participant stated that the side effects were a bigger problem than the incontinence. She also said that she is compliant, doing what she is asked even though there is no difference. One patient noticed a smell and saw her GP who gave her tablets, which did not help. One GP prescribed tablets but said that he could not help otherwise and referred to hospital.

Duloxetine had just been commenced a few days previously by one participant who had no side effects and was looking forward to seeing if it helps. Another woman was offered tablets but said '*they offered me Prozac – I wouldn't take that*'. She also stated that she didn't want tablets. One participant felt that HRT had helped her nocturia. One woman's GP gave her antibiotics for a possible UTI – she is allergic to two types of antibiotics. She started a new tablet and was hoping it would work. Another woman was also taking antibiotics.

Bladder retraining was mentioned with one participant currently increasing her time intervals. Another participant did not have any faith in bladder retraining alone but is better with tablets. Another woman was advised to wait five minutes before going to the toilet in the night but she did not want to do this in case she could not then get back to sleep. She tried staying awake in the night and setting an alarm but this was of no help. She also tried bladder training in the daytime but has other things she would rather be doing and doesn't feel she is a good candidate. One woman had been advised to have inpatient bladder retraining. Inpatient bladder retraining was felt to be ineffective by one participant whilst another commented that it was '*no good as it was not a typical week'*.

Operations were mentioned frequently with one participant feeling that there were still problems after operations but that one of her operations was the best treatment that she had had. She felt that her treatment had been wonderful even though she still had to have a catheter after the operation and still has problems passing urine. Operative treatments had been performed on one woman and she felt that none had

helped. One participant who was performing ISC was annoyed that she had to pay for the catheters. One woman had a catheter for 10 days but did not like it. She would only go out with her husband and was terrified of it coming out when she was climbing in and out of the bath. Another participant found ISC difficult but got used to it and accepted that everything has to be learnt. One participant was not expecting anything of further treatment or of the future. She preferred ISC to leaking. One lady had a TVT and said that five months later '*everything came through again'*. It was no help at all but she wished that it had worked.

One woman had repeated surgery, hoping for a cure but this did not work and she needed oxybutynin tablets. One participant hoped she could avoid surgery with medication and exercises whilst another believes that it is better to have surgery when younger and healthier. She said that her consultant does not feel it would help, she is not bad enough for surgery and it may make things worse. One woman feels that without surgery things will get worse and she would not *'feel human'*. She said that she would not want to be on this planet and anticipates a deterioration, which she could not control. She feels that she would not be able to go to work, shopping and visiting friends would become a chore and she doesn't see the point of being around. She says that she would not feel useful in society.

A colposuspension and a posterior repair were advised within a year for one woman. She expected that this would sort everything out. She also said that she feels relieved that she is going to have more surgery and wouldn't want tablets. A cystoscopy and bladder stretch helped one woman for a little bit. One participant felt

her hysterectomy was not helpful for her bladder and she had believed that this is what the hysterectomy was for.

Staff were mentioned throughout the interviews. One participant described the staff as very caring. Other positive staff qualities stated were honesty, persistence, support, good communication, listening and seeming to believe her. Sometimes women were able to recall things that were said to them in consultations that seemed to have a negative impact on them, '*without doubt I will be seeing you again'*. There were comments about the lack of continuity of care and also a desire to see their consultant or *'the person in charge'*. One participant also detected friction between staff at urodynamics. Other negative staff qualities include dishonesty, concealment and not appearing concerned. One participant felt that staff had an element of secrecy and she felt that she was not being told why things had gone wrong. She felt '*left in the dark and criticised*'. She felt that staff were unapproachable and that she was being told off '*like a naughty child'.* Another felt staff were uninformative '*they don't tell you much do they?'* and she also felt that they didn't seem to know what the problem is. One woman stated that she was not satisfied with anything before her current consultant. She felt that he obviously has an interest and this helps her. One said that her GP didn't know what the treatment would be.

The nurses were praised for explaining everything. One woman said that she felt better because the doctor seemed pleased with her. Communication was important as one woman said *'I know what they are talking about'*.

Resentment was felt by one woman who was told that she would have to live with her bowel problem. One woman had multiple hospital consultations and was told by one person that there was nothing that they could do for her. Some participants notice reactions of staff for example '*he wasn't pleased with something on the scan'.* One woman felt that staff seemed uncertain and did not understand why she had bladder problems. She felt disappointed because certain treatments were not available because of her diabetes.

Some women had some of their care privately for a number of reasons including the level of distress caused by her condition and the length of NHS waiting times. Some women felt that when it came to treatment they were being '*put through hoops*' and it was '*a waste of NHS money'*. One participant mentioned that there was a gynaecology clinic in primary care because of fund holding

- **Urodynamics**

One woman felt that urodynamics was of no benefit. Video urodynamics made one participant feel horrible when she had a big leak. Another woman felt that urodynamics was '*lovely, very slick'*. One woman explained that her explorations were all normal and she says that this drives her mad. She wishes that something would show up so that something can be done.

- **Trials**

A drug trial participant mentioned that she got migraines

- **Impact of bladder**

Bladder symptoms have a great impact on many areas of the participants' lives. In particular physical activities seem restricted but also attendance at family events and even going out of the house at all is a challenge for some. Physical activities affected included keep fit, running, dancing, jumping, exercising, walking and going out for Sunday walks. One woman experiences frequency with swimming while another describes how exercise would be disrupted by the need to go to the toilet and also experiencing leakage. Coughing would cause leakage and one woman said she would '*never dream of coughing'.*

Daily activities were also affected. One participant cannot lift the vacuum cleaner at work because of her problems. Others describe difficulties with going shopping, walking downhill and even going out of the home. Participants describe restrictions in their activities with other people. One woman is unable to play football with her children. Another participant says that she in unable to keep up with her husband and cannot fully participate with her grandchildren. One woman describes how, when out with friends, she has to find a toilet before she can order a drink.

Toilet mapping was a common feature in many interviews leading to geographical restrictions. One participant recalls how she *'leaked all over the floor of an airplane toilet'.* Clothing restrictions were mentioned including one woman who only wears skirts in case she has to '*nip behind a bush'*. She also feels she cannot wear nice underwear.

One participant gives examples of times when her bladder was a real problem to her. She recalled childhood memories of her parents keeping a potty and a sponge in the car and of putting her hand up at school and not being allowed to go to the toilet. As an adult she remembers having to leave two family funerals to find toilets and one occasion when she had to knock on a stranger's door to use the toilet.

Far-reaching areas were affected by the bladder, including hobbies, holidays and general QoL. One woman felt that her problems affected her self, her relationships and sex. Another woman felt that her life had been ruined.

- **Other people**

In many interviews other people were mentioned. Sometimes this was by participants comparing themselves to other people and sometimes it was other people's awareness of their problem. Often there was a secrecy surrounding their bladder problems and a fear of discovery. Women often mentioned their partners and unwanted attention from various sources.

One participant said that her family had all been through similar things with their backs and their bladders and her sister had advised her to get it sorted out before she reached her age. Another woman said that her mother had similar problems to her. Several women made direct comparisons with their mothers. One woman recalls how her mother leaked and couldn't stop and did not tell anyone. She had wanted to help her mother but did not know how. Her mother was *'too shy to buy pads and also stopped going into town'*

.

Participants sometimes compare themselves to elderly patients and express fear for their old age. One participant mentions '*old ladies on the bus that smell of urine'* whilst another was worried she would end up like *'the old ladies in the supermarket'.* One participant works with incontinent patients and feels sympathetic towards them as she compares herself to them.

One participant compared herself to another patient who had had surgery with the same surgeon. Another participant compared herself to her friend, not in relation to her bladder problems, but in relation to them both having marital problems. She also felt that this gave her some support. Support was also felt from staff.

Some people feel better because they see people who are worse than them saying things such as: *'mine is not as serious as some of them' 'another patient has worse problems'.* One woman recalls how she did not wet the bed like her brother did.

Secrecy from other people is evident from some interviews with an avoidance of discussing things and a reluctance to reveal how much things are bothersome. Some participants do not want to burden other people. Other people were often kept out of their problems by them not talking to friends and family about things. One woman said she tells colleagues she is going for a shower at work because of the heat rather than admitting to urinary leakage. One woman feels she can't be open with people. One participant never told anyone for a long while.

One woman described how she passes urine into a bowl at work after a class she teaches. She was worried that a cleaner or caretaker would find her out. She was also concerned that work colleagues noticed her frequency and that she was missing too often. Another woman was worried that other people would be able to tell because of the smell. One woman expressed concerns that other people may notice and she is not able to talk about the problem. The media influenced some participants with one women comparing herself to a woman on the television who was having an operation which she was told was not suitable for her. This made her doubt the medical decision again.

Many of the interviews contained discussion surrounding participant's husbands. One woman said that there were problems with sex but that her husband '*was usually understanding'*. He says to her that he wants to '*make love to his wife'*. He has tried to reassure her about the smell but she does not feel reassured. Other women feel that they can't keep up with their husbands and one said that her husband gets irritated with her. One patient felt that her husband had no patience, which caused arguments. He did help her by making a device out of a lemonade bottle to help her pass urine in the lay-by.

Some people receive unwanted attention. For example one woman's grandchildren and husband make a big thing of it. Her grandson had said to stop running for the bus '*because Nan's wet herself'*. Her children also ask why she goes to the toilet so often. One participant mentioned that her son is concerned for her. Third parties have also drawn comparisons. One woman's granddaughter asked if she would smell like

a lady on the bus. Participants felt that other people would not be able to understand unless they have the problem themselves.

- **Coping mechanisms**

Women describe how they cope with their bladder problems. Most are practical considerations but several women admit to a psychological aspect to how they cope. Some feel that they do not have a choice and '*just have to cope'*. Another women is quite accepting and feels that she '*gets used to situations rather than noticing them'*. One participant feels she can cope by keeping busy and not dwelling on the problem whilst another says she tries to put the problem out of her mind. One woman is determined not to give into conditions and describes how previously she got herself a job as an act of determination not to give into cancer.

Containment measures were commonly described to cope with bladder problems. Many women mention wearing pads and carrying clean pants, tights and pads with them. Pads may be changed for leakage or to manage smell. One woman wears two pairs of pants and feels that this gives her extra support. She admits that this is uncomfortable and does not do this when at home. She also carries her own toilet paper because she feels that by using public toilet paper she could get an infection of her prolapse.

Other devices have been described in some interviews. One woman brings a washing bowl to a class she teaches in, to pass urine in at the end of the class. Her

husband also made a device to help her pass urine by the side of the road. Self-catheterisation helped one women cope with her discomfort.

One woman described choosing particular clothing because of her bladder. Fluid restriction is a common theme for women trying to cope with their bladders. Some generally restrict fluids and some particularly in the evenings. One woman admits that she will drink more when she is at home while one woman limits her caffeine intake. Women tend to avoid precipitating activities. Avoided activities included playing with children and sex. One woman suppresses coughs and laughs but this does not always work.

Preventative micturition and toilet mapping is used in an attempt to control bladder problems. One woman goes to the toilet before going to bed and also before exercise but she says this is not effective. One woman copes with her problem by showering at work.

- **Emotional responses**

Negative and positive emotions are expressed during the course of the interviews. Negative emotions included regret, fear, anxiety, devastation, self-consciousness, low self-confidence, embarrassment, humiliation, depression, frustration, and feeling displeased. One woman described feeling frustrated when she leaks after getting showered and into clean clothes. Others are fed up or hate being wet. There is a feeling of frustration with time and money spent on the problem with getting cleaned up and buying things.

Some women were fearful for the future and worried about getting old. One woman was anxious about the cause of her problems. Another admits to feeling angry and shouting more around period time when she is not controlling herself. Some patients cried during their interviews while other admitted to having cried. Other negative emotions included feeling fraught, abused, like a victim. Some participants expressed self-pity. As though the way the health system treated them made them a victim. Examples of this include feeling like they were '*being put through hoops'* or '*passed around like a parcel'*. Some felt they were not being heard *'I don't think anyone takes me seriously'*. Some women also felt that there were being dismissed. Some felt that their hopes were dashed when put off surgery in case it made their condition worse. Some women experienced doubt in the way they were managed. One woman said that she felt horrible during video urodynamics. One felt awful at the way her consultant spoke to her.

Some were motivated to get problems sorted out. Regret was experienced by a woman who had had a hysterectomy which she felt had caused her problems. One woman felt devastated because she felt she had reduced treatment options. Another wished that the TVT operation had worked. One of the participants expressed disappointment that '*life is not what she expected it to be*' and disappointment about having urinary frequency. One woman said she was displeased '*I don't like this, it never used to happen'*. She was also anxious with a ten-year history of anxiety and panic attacks and she admits to not asking much because she was worked up.

Self-consciousness and a lack in self-confidence were mentioned in several interviews. Embarrassment was often expressed. One woman describes her situation as irritating and embarrassing but is relieved at the plan for surgery. Another woman feels that her embarrassment and feeling of being dirty are made worse by poor conditions at work. She also feels unpleasant and resentful at having to live with the problem and angry, cross and negative. One participant feels that she has got over the worst embarrassment. One lady said she felt depressed due to lack of sleep secondary to nocturia.

One woman felt that she had less stress because she knew that there was no cure. She also felt shy and withdrawn. Another participant described humiliation, anxiety and embarrassment but is now feeling more positive. One woman says that she feels like her '*body is going to pack up'* but she says she doesn't want it to pack up. She feels it is vile and is always aware of the need to go to the toilet. She feels '*desperate', 'appalled', 'the beginning of the end'* and '*feels like life is closing in'*.

One woman complained of frustration, embarrassment, anxiety and disappointment. The embarrassment was at buying pads but felt better thinking that they may not be for her. Emotion was recognised by some of the participants as a cause for their bladder problems.

Several women expressed hope. Hope that tablets will work and hope that everything will be fine. Hope to stop the catheter and go back to normal. Hope that things will change. A participant who was looking forward to a new tablet and her consultant

review expressed hope. One woman said that she never gets depressed and expressed relief at being believed.

- **Normality**

One participant wants to be able '*to do a normal poo'*. Another wanted to stop using a catheter and go back to normal.

- **Expectations**

Some participants have negative expectations with one` women stating '*I know there is no cure'*. She also says on a more positive note '*I know he can't cure me but he can help me'*. She would like to be able to go out and to keep up with her husband. One woman expects the bladder to be fine in the future.

- **The future**

Many women mentioned their future. Some hoped not to need to wear pads and hoped for a general improvement. Some women expected there to be some ongoing problem even with an overall improvement and accept some limitations. There was also generalised fear and concern expressed for the future. This was also expressed by comparison with elderly people. One woman hopes to take long walks with trousers and trainers and not embarrass herself. She is concerned that she will end up like the old ladies in the supermarket and is worried that she will be dirty, smelly and unclean. Another woman does not see things changing in the future whilst a further participant wants to lead a healthy life and not deteriorate. She doesn't want to wear sanitary towels and incontinence pads for the rest of her life. She doesn't want to be thinking about going to the toilet all the time.

One woman feels like her life is closing in, like there is not much time left. She feels older than she is and thinks about physical deterioration. In contrast, another woman expects to be fine in the future. Stopping leakage and to feeling comfortable are the aim for one participant.

- **Concerns (other than the future)**

Sex

One participant explained how her husband left her after she was diagnosed with bacterial vaginosis. She would loose bladder control during sex and therefore avoided sexual relationships. Sex was interfered with by worry about being smelly. One woman said that her husband is okay, but sometimes want to make love. Sometimes she agrees to try but then she just can't manage it. Another participant said that she '*doesn't feel sexy when she is all padded up'* and this affects her sex life.

One woman avoids sex in case of leakage but it is not currently a problem because her and her husband have no sex drive. She is worried what will happen if his sex drive returns. One woman said she used to have problems having sex but that this is better now and she is not sure why. An inability to have sex on the spur of the moment is described by one participant who pre-plans sex because of the smell. She baths and washes beforehand but says that her partner is used to it. One woman

said that she leaks with sex but doesn't have sex because of pain. Another woman said that she doesn't feel like anything when she is leaking and tired.

Odour and hygiene

One participant felt that hygiene and odour were very important. Another said her husband tried to reassure her about smell but that he couldn't. Several participants mentioned smell and feeling unclean or dirty. One participant worries that she may get an infection of her prolapse by using public toilet paper.

Pads

Pads were mentioned in many interviews. One participant complained that the pads were bulky like a nappy. Embarrassed at buying pads was expressed and one woman coped by thinking that they were not necessarily for her. One woman said that the pads don't always cope with the leakage and are expensive but they do help her to cope.

Financial

The cost of pads was an issue for several women. Toilet paper was used instead of pads by one woman but she found this irritating. One woman felt she would rather spend money on her family rather than on continence products.

Age

Many participants mention old women in their interviews. One says she feels like an old woman even though she does things younger women do. One woman said that

she feels old and went on to explain how she thinks things are designed to deteriorate from the age of 40 and not much beyond 50 and she has reached that point. Another woman said that she feels older than she is. One participant is worried about being old but accepts that the body changes with age.

Appendix VII

QUALITATIVE INTERVIEWS COMBINED THEMATIC ANALYSIS (GROUP 2)

The global themes are:

- Emotion
- Cause of the problem
- Effects of other problems
- Start of the problem
- Symptoms
- Restrictions
- Presentation
- Treatment
- Care
- Expectations after surgery
- Postop behaviour
- Self-image
- Other people
- Coping
- Hopes

These are described more fully with examples from interviews.

- **Emotion**

A whole range of positive and negative emotions were expressed throughout the course of the interviews, both in relation to the bladder and other problems. Emotions were also in relation to treatment. Specific negative emotions include frustration,

panic, depression, fear, embarrassment, worry, apprehension and self-consciousness.

Frustration was expressed both in getting worked up and getting frustrated with one's self. One woman described feelings of panic in trying to find a toilet. Depression was expressed with one subject describing feeling '*up and down*' emotionally. One woman acknowledged that she felt low for one week after any surgery and referred to this as her '*postop blues*'. Other subjects said that they felt very low and cried during the interview itself. One woman found that being wet and using towels was getting her down. Another subject described her problems as degrading.

One patient expressed a fear of being alone at the outpatient clinic, preferring to wait back in the waiting room rather than alone in the consulting room. Many women expressed fear for the future. Examples include *'when I am 77 I don't want to be walking around with wee marks on my stockings'*. Fear was expressed by several subjects in relation to getting into relationships and getting older. Some are afraid in case there is something wrong. One women was frightened that if she left it too long it would go back to what it was and as she got older and slower it will get worse if she doesn't get it sorted out now. One woman who had slow postoperative voiding with pain was frightened in case there is something major wrong with her. 'I live in fear that it is something else that may be making it go the way it is. Is there a blockage from making it flow properly? That worries me. I feel if I could get the cause sorted and not leave it that there is something major wrong with me, having the pains down either side'

Embarrassment was a very common emotion. One woman admitted to being too embarrassed to speak to anyone. Another found urodynamic tests embarrassing. One woman felt embarrassed staying in hotels because of the bed sheets being wet. One woman stated that '*anything to do with women is embarrassing'.* Embarrassing tales include one woman who leaked when dancing in a nightclub and had to go home. Leakage outside the home creates worry along with other symptoms such as pain '*I am a martyr to the bladder and the pain'*. Many subjects worry about the future and what will happen. One woman worries about having to wear tissues when walking. One woman said that the bladder is on her mind in the morning and she cant walk well and worries about getting to the toilet on time. One woman says she was worried she may need an operation. Another woman was worried because she had no urge to have sex after her operation. Some subjects found the thought of their treatment nerve wracking while others found complications of treatment stressful and anxious.

'I am frightened if I leave it too long it will go back to what it was. As I get older and slow down I am worried it will get worse if I don't do something to sort it out now'. One woman was apprehensive about having surgery.

Many women are self-conscious. One participant states that she is very conscious of her movements. Another is self-conscious if at someone's house in case the pad won't hold such. Or leakage when sitting on seats, at work, in cars or anywhere else. General negative emotions are described and some subjects acknowledge that they

have a psychological problem in general, while one subject feels that there is a psychological problem as soon as she goes out of the house.

One woman describes putting herself to the test by trying to hold on as long as possible and not going to the toilet. Another participant feels that stress contributes to her problems and has noticed that her bladder was better on holiday. Pads are sometimes worn for peace of mind even though they may be dry. General negative emotions are expressed '*life is a nightmare*'. Negative aspects to treatment were expressed with one participant feeling negative towards the physiotherapist and their treatment. She felt that the physiotherapist was laughing at her.

One woman felt upset when telling her GP about her bladder problems. Another woman describes how she felt awful not being able to take a drink on a night out on holiday as people were looking over at her. Other negative feelings include feeling horrible and vulnerable. One woman describes feeling lethargic because she can't exercise because of the leakage. One woman states that she lost all the confidence she had while another felt she was not confident enough to go out and meet someone.

One woman was blaming herself *'if I was a stronger, more confident, happy person and didn't ask questions...'* One woman was crying because of leakage and having to change in public toilets. Another woman says that she is not happy with the way she looks and wishes to drink a lot of fluid so she can diet but feels she needs to restrict her fluid because of her bladder.

Positive emotions include feeling great after treatment – it changed her life. Women express happiness after treatment and some at being able to stay in hotels after treatment, not having to carry pads around. In general '*all the things I mentioned weren't a problem anymore.'*

- **Cause of the problem**

Patients have various theories on why they are having bladder problems. Many women relate it to childbirth. Such as having big babies, having twins and leaving it too long to have the third and fourth child. Some have vague theories believing it stemmed from the birth or the epidural or that bladder problems are due to having children in general. Another woman describes how she could not pass urine after an epidural and needed catheterised and had to stay in hospital for a week. Previous hysterectomies were blamed for causing or exacerbating bladder problems. One woman felt it happened after a particularly bad episode of coughing.

Some feel it is due to their own behaviour such as holding on too long before going to the toilet or drinking too much fluid. One woman feels that as women get older ladies tend to leak and use towels and she just accepted it. Another woman had felt that a Caesarean section would prevent bladder problems. She said *'silly me'* in relation to her belief.

- **Effects of other problems**

Many participants complain of other medical problems, some related to the bladder and some apparently completely separate. One woman had mobility problems, which makes it difficult to get to the toilet on time. Another woman feels her '*life is a misery'* between her bladder, bowel and back problems. Faecal incontinence requiring pads is suffered by one of the participants. One woman who complains of pain is concerned because she felt it was related to not being able to pass water.

A participant who also has seizures feels that she has difficulty spelling and sometimes adds letters onto the end of words. She says it is '*like some of her brain cells have gone'*. She feels it is safer to have seizures outside as she has previously fallen down the stairs inside. Another woman had antiphospholipid syndrome and feels that this is her '*black mark*' as she has passed it onto her family. She is comforted by the fact that her sister's family can be tested for it and there are scans for pregnancy. Other women complain of back problems and tummy pains.

- **Start of the problem**

This category overlaps with other categories. In particular symptoms, restrictions and presentation. One participant states that she '*cannot remember the start as it was so long ago'.*

- **Symptoms**

Most patients mentioned leakage and/or being wet. Symptoms of SUI include leakage with coughing, sneezing, laughing, walking, picking up children, picking things up in the supermarket, running for a bus. One woman describes how she

keeps choking on things with resultant leakage. Exercise causes leakage for many including star jumps, trampolining, dancing, running, jumping and aerobic type exercise. Minimal exercise causes some women to leak even walking slowly. *'When I was at a nightclub we were doing a dance and it just came away from me. It was so embarrassing, having to go home'.*

Some women describe symptoms suggestive of OAB such as urgency with leakage brought on by putting a key in the door, walking uphill, getting off the bus, standing up at work and getting out of bed. She also describes the unpredictability of not knowing when it will happen. Frequency and nocturia are also described. One woman states how when she leaks her whole bladder empties. Many examples of urgency are given. One woman described having to '*pass urine and poo in the garden and being unable to leave the house without going to the loo, sometimes twice'.*

Toilet mapping is also described. One woman complains of lack of control and leakage after her TVT. Some women describe the location of their leakage '*at work', 'wetting the car seat'*. Or when '*leak in the night if very tired*' or *'if I hold on too long'.* Discomfort is a symptom of some participants when holding on and trying not to pass urine. Generalised discomfort and '*soreness*' was also a complaint. Another woman feels her '*pain is worse when lifting'*.

Isolated statements include one woman who describes urine infections every month and felt that she became allergic to antibiotics. Another woman's symptoms have

been going on for at least 20 years. One woman complains of getting thrush all the time. One woman states that she didn't think her bladder was that serious.

- **Restrictions**

Many people discuss restriction in various areas of their lives including physical activities, jobs, fluid intake, socialising, sex and travel. Restricted physical activities include not lifting anything heavier than a kettle, walking the dog, dancing in a nightclub, using the gym. One participant describes how she has to shower after the gym before she goes to work because of leakage. One woman feels conscious of all her movements. Another woman stopped going to the gym and doing aerobics with the youth club.

Jobs appear to be restricted by bladder problems. One woman is a checkout operator and has to wear towels and go to the toilet often. Some women have difficulty travelling for work and several women have lost their jobs. One woman was made redundant because of ill health but this was not just her bladder problem alone. Another woman was thinking of returning to work as her treatment patches were helping her bladder. One participant, who runs a playgroup, says that she does have bladder accidents when she runs around outside.

Many women feel restricted in their fluid intake. One woman feels she has to restrict fluids to enable her to travel. Another woman describes how she was not able to take a drink on a night out on a holiday and how other people were looking over at her.

Other examples are *'I restrict what I am drinking', 'I don't drink when out for a meal. I can drink pop but a short goes straight through me', 'if I go out I can't drink', 'it stopped me drinking'.* One woman describes how her restrictions have a knock on effect on her family life. One woman who does ISC will not do it when out in public and wants an indwelling catheter.

Some subjects avoid social invitations with one woman making up excuses about going places. Another woman finds that if she is going out drinking she has to go to the toilet every 10 minutes. One woman avoids staying in other people's houses in case she wets the bed.

Sex is restricted for many women with avoidance being common practice. Another says '*you could rarely have sex because you will wee*'. Another woman feels that she '*shuns away from the whole sex act'*. She is unsure whether to risk having the pad off or having to get up out of bed, take the pad off and wash. She said it is easier to pretend she is asleep or has a headache and says '*you don't want a woman going to sleep in a nappy'*. One woman describes how she is frightened to get into a relationship. She doesn't feel confident and doesn't go out to try to meet somebody.

Several women describe restrictions going out. One woman says that she feels there is a psychological problem as soon as she goes out. Another says that she refuses to be kept in but does get '*caught out'* when she is out. Other quotes include '*I tend not to go out'* and *'it stopped me going out as much'.* Toilet mapping restricts some subjects. One woman is restricted staying in hotels because she is embarrassed at

the sheets being wet. Some women describe needing to take extra clothes on holiday and having to carry spare knickers and clothes around. Some women have to keep changing. One woman said that she would like to wear thongs again but she has to wear proper pants.

Travel restrictions were common. Some women have to keep stopping on their journeys because of the bladder. Some describe wetting the car seat, which took three days to dry out. One woman described how she was on a surprise trip for her 60th birthday and did not allow the leakage to spoil the trip. One woman describes how wetting the car is not as bad as getting caught out on a bus. One woman described how she wet the bed sheets on her holiday. She washed them and then dried them with a hair dryer. Fluid restriction was practiced on holidays. One woman says she wont drink after 6 o'clock but her partner drank three pints while she sat with nothing in front of her and this made her feel awful. One woman's mother has asked her to take her away but she is concerned in case she had an accident even though there are service stations.

Many women describe restrictions in their choice of clothing. One woman says she could not wear a skirt 'a wet patch on a skirt is obvious for miles'. In contrast another feels she has to wear a skirt as she finds that easier to change her clothes if necessary. Some wont wear trousers as they are hot and sweaty or because of having to wear thick pads. One says that she had to wear shirts but liked wearing trousers.

One woman says that because she leaks with exercise she avoids it and has consequently put on weight. Another woman describes the increased time it takes to do things. She has to shower and go home to change after exercising before she can go to work. One woman feels that SUI is less restrictive than urge *'at least with stress incontinence you can cross your legs. With urge you have no idea when it will happen'*

Some women mention restriction in general. For example, one woman mentioned that she feels restricted by her urinary frequency; another feels that the restrictions hold her back. Others say *'life is a nightmare', 'it has affected my whole life – I have not let it upset my life'*. One woman feels she does not have a life at all. One woman describes how life is affected more than you realise. Another woman says that she can't do all the things she wants to.

- **Presentation**

Different woman had different reasons for their initial presentation. Some women describe SUI as their reason for presentation. One woman was suffering from a bad chesty cough, she felt something '*happen in her stomach'* and she started to wet herself. Another woman came because of leakage with physical activity. She noticed a small amount of leakage when she started to take up running again in an attempt to get fit after a hysterectomy. She found it was starting to affect her work and time.

One woman was very conscious of her movements so she *'finally gave in and went to see my GP…I waited and tried to overcome it with exercise and muscle control but*

it didn't make any difference'. One participant presented when she felt that her pads were not enough. Some women had delayed presentation because they are not aware that there are treatments for UI. One woman had presumed that there was nothing that can be done and there were no treatments other than physiotherapy because there are so many advertisements for continence pads. One woman delayed her presentation because of embarrassment. '*I waited because I felt conscious. I tried to overcome it by exercise and muscle control – it didn't make any difference*.' She also suggested *'If there was a questionnaire that could be sent out to people with a problem… you are embarrassed at a consultancy. If you could answer questions before you got to the consultation that would benefit both parties'*

One woman's children kept complaining that she smelt and this prompted her presentation. She also said *'that is what brought me here; I could have lived with it. I need to be healthy cause I'm a childminder'.*

One woman presented because she thought that she needed an operation. Some women presented with other complaints such as bleeding. One woman went to her doctor because she had swollen feet. Her GP prescribed the gym but she could not go because of her bladder problems and this is how they came to light.

Another woman describes *'I went back and forth to the doctors and they didn't do anything. Once I saw the male doctor and he referred me because he was male and didn't want to examine me'.* One woman found it difficult because she works for her GP. She waited until there was a locum. One woman said that there is a help line you

can ring so your GP doesn't have to be the first port of call. She felt that if that was advertised it would be helpful. She had not been aware of it. She also suggested that if there was a questionnaire paper that could be sent to people with a problem that may help with the embarrassment at the consultation. She felt she was asked medical questions but not how it affected her socially or her sex life.

- **Treatment**

Information

One woman said that her GP gave her leaflets. Some woman felt that people were not aware that there are treatment options. Another woman descried a help line *'There is a help line you can ring so your GP doesn't have to be the first port of call, if that was advertised. I don't know how long that has been around. I didn't know about it'*

Fluid advice

Some participants found that avoiding tea and coffee made a big difference, even without other treatments. One woman was told to drink more fluid but was then going to the toilet. Another woman said '*the doctor said it was a fallacy and that drinking less doesn't help'*. One woman wanted to drink a lot of water as part of a weight loss diet. She was especially keen to loose weight in case she needed an operation. She also admitted that she is not happy with the way she looks.

Ring pessaries

One woman said that ring pessaries were not successful.

Exercise and physiotherapy

There were both positive and negative comments about physiotherapy. This group of patients all had operations and so would therefore be expected to have had previously unsuccessful physiotherapy treatment. Positive comments were *'it helped a bit', 'it helped initially'*, *'they did improve but not a cure'*. One woman said that she knew about pelvic floor exercises.

Negative comments included '*I exercised too strongly and too often', 'I felt negative towards physio and their treatment', 'I Went for months. I improved, but not enough', 'Physio said I had better pelvic floor than her. I could do pelvic floor exercises'.* One woman felt that the physiotherapist was laughing at her and this made her feel bad. Another woman was given treatment to do at home but she stopped because of the way it made her feel. Another woman said she was told that her improvement was limited. One woman tried using weights, which she said '*were alright but did not solve the problem'.*

.

Other comments about pelvic floor exercises include:

'*I had that thing like a vibrating thing with shockwaves to see how strong the muscles are'*.

'*I have a weak pelvis and cant do the exercises very well. I did them for quite a long time – I came for a month or two',*

'*I know when you need to go to the toilet you get your muscles, you know, it just doesn't work'*.

'I always knew to do the pelvic floor exercises. I have the cones. I used them but not a lot. I talked to friends and practice nurse at the surgery'

'I thought how can you do physiotherapy? I was examined. The muscles were strong and it was more than that.'

'Pelvic floor exercises – I had been doing them on a daily basis without realising for years, probably since the children were born'.

Continence adviser

One woman said that the continence adviser did bladder scans and referred her on after that.

Nurse clinic

One woman comments that *'the nurse clinic is good and they have more time to explain things to you and are not so pressed'.*

Bladder retraining

One woman said that she found bladder retraining difficult. One said that she needed to go to the toilet within 15 minutes of drinking fluid. Another woman felt that it made a big difference. A participant was motivated saying she was *'Giving the bladder drill the best shot and if things stay the same I will manage'*.

Some participants had undergone inpatient bladder retraining but complained that they did not know what to do the first day. They felt that they had wasted a day. '*For all I knew it could be marching up and down the ward', 'There was a feeling on the ward that not all the nursing staff were enthusiastic about bladder drill'.* One woman acknowledged that it was challenging but felt that she benefited greatly *'The week was extremely tedious. Difficult and very hot. The following week I was virtually in tears. I had to talk to myself to try to relax. I reaped benefits from it.'* Some women compared themselves to other patients who were in hospital at the same time as them. *'There was another lady in – worse than me. We were together all the time. She was a bit better and I could see it does work'.*

.

One woman did not want to wear pads, which is part of monitoring leakage. *'I was told to wear pads but I through them away – it was a step backwards'.*

Surgery

The majority of women in this group had undergone a TVT for SUI. Some had a colposuspension instead or as well. Some had undergone other pelvic surgery at the same time or in the past such as vaginal repair. There were a great deal of comments about surgical treatment and these have been analysed in the following subgroups:

1.Positive comments about surgery

2.Complications and negative comments about surgery

3.Decision for surgery

4.The procedure itself

1.Positive comments about surgery

There were some positive comments about TVT operations. *'The operation has worked', 'the op was a doddle. Best op I ever had', 'I feel I have been cured'.* One woman said that she found it great. She had been given a leaflet and had decided to have it done. Local anaesthesia was used for one participant who commented that she never felt a thing. *'It was a successful operation, successful straight away'. 'I went back to the gym for a short time. I didn't need to wear pads anymore – so it boosted your confidence'. 'I wasn't wet at all'. 'No leakage with sneeze or cough'. 'I did try a little bit of running and jumping with a full bladder and there was no leakage'. 'There was an improvement. I wasn't wet at all. The only thing was it was slow. It has slowed down a lot now to what it used to be.' 'The TVT is brilliant. I believe that before it was a big thing – the operation.' 'It was a very short recovery time and the effect was instant'*

.

One woman comments that at her review appointment *'everything was fine. Asked to cough and didn't pee which was amazing'.* There were descriptions of reduced frequency, the ability to get out of bed without urgency, not having to plan things ahead. There were comments '*I felt okay for the first time', 'I am happy to stay in a hotel with women cleaning the beds without embarrassment', 'it is amazing what a little bit of tape can do to get your life back'.*

One woman describes how she feels she must put her trust in her health professionals '*I have to believe it will work, I have to trust the person doing surgery, I wasted time not having surgery sooner', 'surgery was very good', 'the anaesthetist was very reassuring'. 'I did try everything other than surgery. I suppose you have to do that. I did come in positive that it would change my life and it has' 'The hysterectomy and bladder repair – helped for a bit'*

'I was happy with the first part of the operation. It stopped the embarrassment of the leak when I cough or laugh. As the years have gone by I had to restrict what I am drinking and have to go more frequently to the toilet'

'After the catheter was out I was able to go longer and didn't go so often. I just felt like I had a new bladder. It was marvellous. That is why I know it has come back now with a vengeance.'

'I had a few minor hiccups but that was okay. I was brilliant, I couldn't wait till I got my first cold'.

2.Complications and negative comments about surgery

In the interviews there were many negative comments about stress incontinence surgery. Postoperative complaints included needing the TVT cut, urinary retention, abdominal pain, tape erosion, difficulty passing urine, incomplete emptying and pain for 3 or 4 days,

One woman's SUI was helped but she still had other bladder symptoms '*the TVT stopped leakage on coughing but I still had lots of leakage and lack of control'.* Another hoped to get back to full time fitness but two years after the operation she is getting urge incontinence and started preventative micturition and fluid restriction. She is worried incase something was wrong with the operation and was told it wasn't a tape erosion, video urodynamics showed OAB. She wanted to know what was causing it as much as resolving it.

'*I have irritability. Plan everything around the toilet and be careful what I drink. It is one thing after another. The complications were very stressful and anxious'*

Some participant had voiding dysfunction. '*After being to the toilet a little bit will drip'* One does ISC but there are no facilities for this at her workplace. One woman had a TVT and posterior repair and commented how she felt prepared and knew the risks. She was unable to pass urine postoperatively needing a prolonged catheter and then ISC. This woman was planning to have her tape cut hoping it would improve things. Some described difficulties emptying their bladder. *I was very heavily bruised. Very swollen. I had to be catheterised for 6 days to let the bruising subside and for everything to settle down'. 'Not emptying bladder fully and the best way to go to the toilet was to stand up'. 'Postop I was weeing slow'*

.

One woman was upset at needing the tape cut. *'A little bit will drip after I have been I feel a little bit more come' 'When I used catheters it didn't help. Something I ended*

giving up on'. 'The catheters on my GPs prescription were too big. The hospital ones were a lot thinner'.

Pain and discomfort were mentioned. One woman was sore for three or four days with the result that she missed work and missed out on her own birthday celebration. *'I have always got a discomfort like the bladder is full, even when I have just been to the loo, there is a pressure feeling – I don't know if patches would alleviate that – from what I was told I don't expect it to.' 'Postop I have pain in the side. Doesn't know what it is. Is the pancreas above the bladder?'* One woman who had pain after a TVT turned out to have an ovarian cyst.

Some women have ongoing leakage. One said she expected to hold on and leak less often but this is not so and she wears pads

Tape erosion was described whose her husband was ripped on intercourse. She said she was initially told it was scar tissue and given anaesthetic cream and tablets. After the tape removal she still had pain on intercourse, groin pain and leakage.

Some women had UTIs. One woman was expecting to hear about a postop TVT study but did not. She had several infections and feels like there is something waiting to come out of the urethra. '*I feel I have more urinary infections than I used to. I don't know if there is anything else that can be done about that'*

'My wound split open and I came to hospital very other day to get it dressed, not a nice experience'

'Post-TVT – I thought 'oh my God what have I done'. Lost weight, stayed at home for a couple of weeks. Did what I was told. Was not exercising so it wasn't at its worst Started getting back to normal but still got cystitis, stinging, pain. Took antibiotics but no better'
'I was told everything was fine postop – I felt demoralised – do they think I am exaggerating?'

One woman had a Marshall Marchetti '*I think I was a guinea pig – only 6 of us in the country. It was a sling. I think if it was a normal repair it would have been better. The women who have had these have had problems'*

Sex was painful after a colposuspension
One woman was surprised at the blood loss with TVT and said that this was not explained to her. One woman describes a dent where the sutures were. She had it removed under local anaesthetic.

3.Decision for surgery

Some women felt as though they should have the operation without a lot of consideration. *' The consultant suggested TVT straight away. Told me it would be amazing, change my life, not like the old days. I would be out the same day.*
It all sounded so simple. I didn't get any other options'

One woman says that she was told to have incontinence operation along with hysterectomy, as she would probably need it in a couple of years. She was fine for a couple of years after surgery. She was then advised to have a further operation (vaginal repair) and has had voiding difficulties since.

Some women did feel that they were informed of possible complications: *'Mr… explained the complications. I had every one of those complications on the green sheet'. 'I was told there was an operation but it was new. I waited over 12 months for the operation. He did point out that it would improve the stress incontinence but it may make the urge worse. I thought that would be easier 'cause you know when it is going to happen.'*

Some participants said that there were operations, which they were not allowed. *'I was not able to have a colposuspension because of four caesarean sections and too much scar tissue. I had the TVT'.*

One woman said that she was apprehensive about having surgery. *'I don't like messing with my body. If something can be done without intervention then I'll follow that process first'. 'They are doing everything so I don't have to have surgery – I'll give them that. I'd do anything not to have surgery.'*

Some women tried to conceal the fact that they were having a bladder operation. *'I had it when I was off work and not to have to tell people what you are doing'*

'I was worried I would have to do catheterization. She gave me a couple of lessons in that'

One woman commented on how the anaesthetist was reassuring. Another praised her surgeon saying '*I could hug him, I think it is just wonderful it was very stressful and anxious'.*

4.Procedure itself

There were some comments about the anaesthetic. *'They couldn't get the epidural in because of osteoarthritis. He said you have to get fluid out before you can put it in. he had the right nerve, I felt it shooting down my leg. He did a different anaesthetic, which was brilliant. I was able to talk to Mr_ during the operation and didn't feel a thing. I had the advantage over the other ladies; they had to stay in bed because of the epidural. I could move about and that worked well'. 'I was lucky to be a day case having just local and sedation. Within an hour I was having a cup of tea – that was nice'. 'You don't have that sick woozy feeling. I am glad I opted for that because I felt much better. Went home at 7 o'clock'*

One woman commented on her incision: *'I had a problem with the stitches. One side had a dent and a lot of pain. Apparently it is like putting a button in, you put a stitch in and it pulls down but it hadn't happened. He put in some local anaesthetic and removed it. He said at least it was me, working there I understood, other ladies wouldn't have.'*

One woman felt very sick the morning after the TVT. One was in for 3 to 4 days, sent home with a bag, woke up with excruciating pain and went to hospital with a UTI. *'The procedure itself wasn't a pleasure but it wasn't degrading or anything like that. It went very smoothly and neatly'.* One lady who was expecting day surgery said '*I was late having surgery and had to stay overnight.' 'It was a bigger operation than I thought. Because it was a local anaesthetic I'd assumed it was minor. When I came around from the anaesthetic I thought I was in the morgue. I was sick and so cold.'*

'I was supposed to have an epidural so you can cough and adjust the tape. They couldn't get it in… I had a different anaesthetic. I could talk to Mr ___, during the operation and didn't feel a thing. I had the advantage over the other ladies. They had to stay in bed because of the epidural. I could move about and that worked well'.

Catheters

'I got the bag and was clamping and unclamping it myself.' 'When I used catheters it didn't help – something I ended up giving up on.'

Several of the participants had to practice ISC. One woman said that she became sore and needed to have the urethra widened. Another woman said that she did not realise you could get UTIs with ISC saying 'I am not a medical person'. One participant said that she is fine doing ISC at home but will not do it in a public toilet.

Another woman said that she das a mental block with ISC. She feels this was a combination of a family member having cancer and one of her friends told her that she could perforate her bladder doing ISC. One woman had four admissions with burning, urgency and leakage. One woman did ISC to prevent a leak when she had urge. This was around seven times a day.

One of the participants feels that she would prefer an indwelling catheter so she can have more freedom and to avoid discomfort and pain. Other comments on ISC included *'I hoped I would not need it', 'I tried it before. It made me determined that I would not need it'. 'That is the worst thing - coping with living and then having to self catheterise'. 'It is not a pleasant thing to have to do is it?' 'I had to learn to self catheterise – I did not like that at all'.*

The thought that it was short-term helped one woman to cope with ISC, *'She did her best to reassure me that it would only be for a couple of months – which helped'.* One woman who did not need ISC commented that *'the worst thing was going to self catheterise but I don't have to'.*

The size of the catheters made a difference to one lady. '*After the operation I was told to use catheters to check on emptying properly. The GP prescription catheters were too big. The hospital ones are a lot thinner'.*

Some woman felt that the suprapubic catheter seemed less drastic and easier to cope with. One felt that it was not too obvious and that work colleagues would tell her

if it was obvious. Another woman commented that she was not ready for something permanent. One participant said that she was allowed to decide for herself.

Infections complicated some of the cases. One woman felt she was not prepared for that. In contrast another woman wished she had the suprapubic catheter as she found it easier to cope with.

Tablets

Several of the participants tried tablets for their bladder. It was not always clear if they were anticholinergics for OAB or duloxetine, for SUI.

For some woman the problem was lack of effectiveness or side effects. One woman said that she tried lots and none worked. It is likely that these were anticholinergics. Other comments about effectiveness included *'I tried detrusitol. It is not help yet but it is only two weeks', 'Duloxetine – didn't work', 'I have tablets. I don't know what they are called. Stress incontinence tablets. They haven't relieved symptoms, haven't worked. This test (ambulatory urodynamics) is because the tablets don't work'.*

Side effects were a problems for some women '*I tried tablets but I got a dry mouth – I decided to put up with it', 'I got reflux and acid coming onto my mouth'. 'I felt sick and it reduced my quality of life', 'I couldn't pass water. I rang the national help line. I was referred to hospital and told it would resolve when tablets wore off and it did.'*
'I was conscious there may be side effects. I ran out of prothiaden years ago and was up the wall'.

One woman had oxybutynin in a research trial and it gave her headaches. Duloxetine is also used as an antidepressant and this posed a problem to some *women 'I did not want to take one which was an antidepressant'.* Some women were keen for tablets. *'I felt cheated because I thought they were going to be the answer'.* In contrast other women were anxious about tablets '*The doctor suggested the time release ones but I did not feel confident to do it'. 'I am always reluctant to take tablets'.* Some women say that they were never prescribed any medication by their GP or urology.

Patches

There were positive and negative experiences of oxybutynin patches.

'I asked if I could try patches. I felt rejuvenated by it – they slowed down bowel and bladder I thought I may get back to work.' 'I had a reaction to the patches'. One woman was aware of them but had not tried them 'I haven't resorted to patches but I know it is available if I want it – we are just at the decaf stage at the moment'

Pads

Many of the women were using or had used pads in the past for leakage. *'I wore heavy pads, I changed them every 2 to 3 hours', 'Pads and clothes would get wet', 'I had to carry pads all the time', 'Leakage would go beyond a pad – it was horrible', 'Wearing pads all the time', 'With a period it is just 5 days. With me it is 7 days a week, 24 hours a day', 'The pads were not enough when I had a particularly bad*

cough', 'I Got pads to go to Disneyland and saw the consultant at the airport – things like this is what happens'.

One woman admits to wearing pads for psychological reasons to feel secure *'Wears pads for peace of mind but usually dry'.*

Several woman comment on the expense of using pads '*costing a fortune but getting social worker and district nurse to come out', 'Pads cost a fortune – my daughter is a district nurse and got me a big box of pads and a kylie mattress'*

One woman worries about discovery via pads. On holiday she did not want the cleaners to see pads in her bin in the hotel room so she put them in other bins.

Injection

One woman had an injection but is not sure that it was. Another was referred for injections but then found that they didn't do them. One thought that the injection would not give the desired result and would have to be repeated.

Stem cells

'They are doing something on stem cells – then operation would not be needed'.

Future

' I would have a further op if there was 70% chance of no pain and light leakage'

Cognitive psychology for pain

'Instead of picking lots of spuds, just pick a couple and relax and enjoy the garden'

Waiting/delaying

Feels she waited a long time and put up with things for a long time.

- **Care**

Some participants recognised their own roles in their management. One lady describes how she was allowed to decide her treatment regarding the use of catheters. Another woman described how she chose to opt for private care as she thought that this would have a fast pathway. One lady described how she requested to see someone specialised. One woman admits that she did not ask any questions before her TVT operation. She saw it as a week off work and a way to get some attention from her husband and some respite. One participant said *'I don't mind what treatment I have – I'll take it!'*

There is some reluctance to seek help in the first place '*I have been fortunate plucking up the courage to admit to someone that there is a problem. Even though I work at a GPs it is easy to ask for someone else'*

Negative care

There were negative comments regarding referrals, waiting lists, waiting times, changes of consultant, changes of medication. *'At first they didn't really do anything. I*

was fed up with the lady doctors not helping me. They didn't really say anything. As we get older. Ladies tend to get a bit of a leak and use towels. I put up with it'.

One woman observed how the consultant in the NHS appeared rushed. One woman describes an outpatient experience where she felt embarrassed as she lay on the bed and leaked in front of the consultant. Another woman comments on the history taking she received '*I don't remember being asked many questions about whether it did affect your sex life or how it affected you socially, it was more medically, is there a problem? How much leakage – but there is a lot more to it.'*

There are negative comments about surgery information. One woman said that she was not told what to expect postoperatively. One felt anxious waiting six weeks for review. Women did not always feel that they had a choice of treatment '*the TVT – it sounded simple. I was not given any other options. I Went along with it because the consultant was recommended'*

Women made positive comments about the way in which they were treated. They appreciated their privacy being respected. *'Ward staff showed respect drawing curtains', 'Clinic staff showed respect for privacy'.* Information giving was also seen as a very positive aspect of care '*Postop review everything explained, feels more positive', 'The people I have seen have been very helpful and informative.'*

When women felt that their carers were understanding this was appreciated, even if their knowledge was incomplete '*GP very understanding', 'GP said she should have told as there is a cure. Didn't know how good it is but something as to be better'* Women also appreciated the determination of the hospital staff to help '*The consultant never gives up, makes sure you have as good a life as possible. Never says 'I cant do anything more for you'. 'The nurses never give up'.*

Women made a variety of comments about the care they received from their GP. Some women said that their GPs did not do anything initially '*I went back and forth to the doctors and they didn't do anything', 'they didn't do anything at first'. 'Fed up seeing lady doctors who didn't really say anything'.* Referrals by GPs were described *'Gave leaflets and referred to hospital', 'One day she saw a male doctor who didn't want to examine her and referred her', 'Difficult because I work for my GP. Went to see a locum who referred me to a gynaecologist with a special interest in urogynaecology'.*

Other interesting comments included '*At one point suggested it was all in my mind – referred to psychiatrist – had cognitive psychology for pain', 'Advised pelvic floor exercises', 'GP told her about TVT and suggested seeing the consultant who did the hysterectomy'.*

Most of the women had urodynamics and made comments about their care during this. Some felt it was embarrassing. Some felt that the nurses were great. There were descriptions of the process with *'tubes and wires'*. One woman commented that she

had to have urodynamics before physiotherapy but had met another woman who had physiotherapy without urodynamics. Other comments *include 'Not unpleasant'. 'I did urodynamics where you jump up and down – he said I was fit and healthy which should help'. 'I had fluid put in and was told I might wee slower but that did not really matter'* and regarding ambulatory urodynamics *'if this test proves I need doing – I'll do it!'*

Some women feel their care did not prepare them for UTIs with ISC. Some women were nervous about attending or self-conscious not wanting people to make a fuss.

There were many comments about lack of communication. One woman complained that she was not told what she needed to order when she was discharged from hospital – her niece (a district nurse) advised her. Another woman commented that getting through to the GP is difficult. A woman tells how her GP could not find her urine test results. Some women felt that they were not told things about the operation *'No one tells you (the operation)', 'No one ever told me (the operation)'.* '*They think you understand but you don't – I didn't understand you may be left with urge incontinence'.* Another comment was *'Medical people may not listen because they have heard it all before'.*

Time was felt to be a factor in poor communication. *'In hospital people don't have time and are busy. Medical people don't have time. They think 'you have got this and we can do this'.* One woman said that a doctor shouted at her for drinking caffeine. Also he used the term *'maxed out'* and said that he '*can't presume I know what that*

means'. Other suggestions included '*Women talking to women might be more beneficial' and 'an informal atmosphere might be more beneficial'.*

'I don't know what the operation was, cause no one tells you'. 'Then I realised with a Burch colposuspension you can get urge incontinence instead of stress incontinence'. 'I believe there are other treatments (other than TVT) – physiotherapy, exercises, cones, uninvasive surgery. He had explained what a good and bad bladder was – I was in the middle'. 'There was nothing he said which mad me feel afraid of surgery. If I had been aware of things I don't think I would have had it. I would have liked more information'

Another woman was told that she would be seen in six weeks but not sent an appointment – she had to phone up to make the appointment.

'The catheter company is good and discrete.'

There was a perception that private care was quicker but also that there might be a faster recourse to surgery which one woman regrets. '*My GP said it would take a long time on the NHS. I went NHS after my first consultation and found it was quick'.* Another woman contacted BUPA because she had it anyway and was advised to contact her GP. One woman commented '*Sometimes I wish I didn't have BUPA. If I had been NHS I don't think they would have done surgery first'.*

Continuity of care was noted. '*The TVT was cut by someone other than the initial surgeon – or at least he didn't speak to her'*

There was dissatisfaction with staff '*what he says today is not good enough. I want to get back to work'*. One woman feels that an ovarian cyst should have been picked up earlier. '*Tape erosion was missed the first time. It took a second opinion to pick it up'. 'Consultant didn't explain alternatives'*

Positive comments included *'I could not fault anyone'* and *'the consultant was nice'.*

There were several comments about staff such as:
'Lovely doctor with brown eyes', 'The operation was done by a doctor who was about 10 years old'. 'He said 'I am going to insert 2 fingers to test things' how can you take that seriously?' 'When you go to see a specialist you expect they know what they are doing'. 'He told the trainee 'dry mouth, dry knickers". The patient did not understand this.

'We tend to put doctors on a pedestal'. 'A different consultant was warier of encouraging the operation unless they really have to.' 'Medical people sometimes don't have the answers'.

One woman commented '*this is one of the best. My mother found other hospitals unpleasant, uncaring and dirty.' 'It has a caring feel. Like people are going to look after you'.*

- **Expectations after surgery**

These included no more leakage, not changing pads, not wearing panty liners, a cure, and an improved life.

'I came in positive that it would change my life and it has '
'Told vagina would be like a 40yr old. How would anyone know?'
'I was expecting something miraculous but I didn't feel that'
'I felt I would be free to take up my sport fully. I think that by doing that everything else would fall into place as well.'
'Not being conscious of the bladder'
'Just taking the whole thought out of my mind and getting on with my life in general'

- **Postoperative behaviour**

This includes clothing choice '*I always wear trousers'*, effect on mood *'I felt much happier that I don't have to carry pads around with you*,' the ability to exercise '*I went back to the gym for a short time', 'I am a lot happier. It really makes me happy'* and transport '*chose not to drive. Husband drives everywhere – makes her mad'*

People are able to pursue interests *'I joined a slimming club – doing well' 'Wants to get on with life and do things' all the things I mentioned weren't a problem anymore 'Bladder much better on holiday'* She feels it may be related to stress.

Some people still toilet map *'I plan everything around the toilet – irritability'. 'Don't like toilets outside the home unless I have to'. 'I check out where the loos are just in*

case'. 'I am not comfortable going somewhere if I don't know where they are but it probably is less of a problem'.

Sex life was improved for some *'I didn't need a pad in bed. It was more spontaneous, before I had to think, do I risk having the pad off or do I get up, take it off and wash.'*

'Not such a problem. Learn to deal with it in ways that best suit your way of life'

I didn't need pads anymore so it boosted your confidence.

- **Self-image**

People feel older or worry about age *'I am a 43 yr old woman and it doesn't look good', 'Daughter says 'you have more wrinkles than Nan' and it is true', 'Mother says ' you are too young"*

There are also concerns about feeling normal 'It's not right is it?' 'You feel abnormal' 'Would like to be able to stay in bed – to be normal'

Sexuality is a concern '*I am not a proper woman. I can't give my husband what he wants' – not able to have sex for 11 months'. 'Postop lost urge to have sex – that worried me'*

One woman had split up with her husband but is worried if she gets back with him she wont be able to have sex.

'I have not let it affect my sex life – I am on my third partner'. 'My first husband was not a very loving man but he was sexual. The man I am with is very loving and I would like to have sex' 'not able to have HRT because of antiphospholipid syndrome, tried Replens and KY jelly'. 'Colposuspension made things worse. Tried sex once but it was very sore it affects your femininity (going to bed in pads)'.

There are many comments on hygiene '*Will not do ISC in public toilet' 'Baths are important – you feel cleaner' 'You are always using wipes – never go anywhere without them' 'Felt dirty, smelly. Tried to cover up that there was a problem' 'You feel dirty'*

Self-confidence was an issue *'Wore protection to feel more confident' 'Doesn't feel confident when people comment on her frequency' 'Improved postop – not having to wear pads' 'It affects your confidence'.*

- **Other people**

Many comments surround other people and some people cope with this by treating it as a joke. '*Only my husband understands how it has impacted'.* One woman's friend told her she could perforate her bladder with ISC. One woman's boss would say '*are you coming?'* While she is standing trying to get bladder control. Another woman's mother says '*you are too young'*

People compare themselves to other people '*At work some people can go practically all day and I am going….*' (Talking about frequency).

There is a fair bit of secrecy, not wanting anyone else to know. One woman had her operation when not working so as not to have to tell people. One woman did not want to have to tell the insurance company what it is when it did not fit into their classification.

'You don't go round telling people'

Women often compare themselves with others '*When you come into hospital you realise other people are worse off than you', 'Talking to other people in the waiting room I found I should count my blessings', 'Talking to other people with similar problems is a huge benefit',*

One woman has a friend who has to hop onto the sink – she wishes she was light enough to hop onto the sink herself!

'My mum had problem and was not successful – because I am fit and strong there should not be a problem', 'Sister had electrodes inside which helped', 'There are lots of people worse than me. I worked for Samaritans and a crohns group
My friends have had colostomies and my daughters' pregnancy losses',
'Other patients won't go out – I refuse to stay in because of it', 'at work in cold weather some people can go all day and I am going…', 'only when you talk about it do you realise how many people have it'.

Many participants recognised that for them talking to others with similar problems was helpful. One woman made the suggestion that in outpatients *'Stick everyone in a room and be late so we are forced to talk to each other!'.* Other comments include *'Women talking to women might be more beneficial', 'Talking has been the most enlightening thing', 'my mum and sister know but not the full extent'.*

Women comment on their bladder problems being noticed by others *' I am not able to take a drink on a night out on holiday', 'Friends say 'oh are you going into hospital again for your bladder?'* One woman feels that getting caught out on the bus is a worry but it is not so bad in a car. One lady describes how she was witnessed getting caught out just before a meeting. *'I go every 10 minutes – they say cricky and make a joke about it. It make me feel not confident though'*

Partners, and husbands are mentioned *'it probably affects the partners. I didn't ask mine. We've been together for 45 years. I am sure it affects them. It is bad enough being hormonal. Do I touch her or don't I? Helpful to talk over things like that. Wouldn't be comfortable talking to husband about that'*

- **Coping**

Many women employ various strategies to help cope with life with bladder problems. The more common strategies are restricting fluids, wearing and carrying pads and planning or restricting activities because of bladder symptoms.

Many women restrict their fluids but the extent and circumstances vary. One woman says that she could not go out if she drank. Another describes the conflict she feels because she has to fluid restrict but also believes that water is needed to keep healthy. Some women avoid alcohol as well as fluids in general, particularly if going out e.g. for a meal or travelling.

Many women state that they wear pads. Some women admit to wearing pads for peace of mind or to increase self-confidence but they are usually dry. Many women carry spare pads. One woman commented on how postoperatively she changed from lady pads to panty liners. One woman started wearing pads for certain situations only. Another woman describes how she wore pantyliners initially and then as the problem got worse the pads got thicker. Several women were conscious of whether the pad is going to hold if at someone's house, sitting on seats, at work or in cars.

People coped by restricting risky activities *'I worked a system that didn't embarrass me or put me in embarrassing situations', 'I stopped most of my sport and going to the gym – just relied on road running so I was near to home and if my shoes were full I could get in the shower as soon as I got home'.*

Women often have to plan things around their bladders. One woman described how she makes sure there is a toilet wherever she is going. Fluid restriction is practiced as a form of trying to plan for travel.

One participant copes with her bladder by treating it as a joke to other people. In an emergency one woman describes having to pop behind a bush to void. One woman says she just gets on with it, as she is a mum. One woman holds on to test herself.

Containment measures are used a pad and hand towel under pyjamas, a towel on the bed, a bath towel on other friends sofas, tampon and sanitary towel if going out, tissue paper when walking. *'I have to wear pads. With a period it is just 5 days isn't it? With me it is 7 days a week, 24 hours a day sort of thing'*

Preventative micturition and toilet mapping are practiced. One woman always voids before a meeting but knows that in bladder training they are taught not to go 'just in case'. *'I make sure I go to the toilet. I try not to hold it in and just go'. 'I make sure I go to the toilet before I leave' 'When I go out anywhere I know where the toilets are'*

Physical measures help some. '*I would stand and wait to get bladder control before I could move at work'. 'Crosses legs to sneeze'. 'When playing with children, I sit on the floor and I don't bend over, try not to pick them up unless I'm at their level, that's a pain'.*

Clothing helps coping with carrying spare knickers, wearing a skirt so she can change, never wearing trousers that get hot and sweaty, carrying spare clothes and keeps some under her desk, keeps spare shoes and tights under work desk.

Some women use various receptacles such as a potty under the bed, a margarine tub.

There were various other comments on coping. Some women feel they can't cope and some have learnt to rise above it. Hygiene is *addressed 'baths are important, you feel cleaner', 'wipes, always using them. Never go anywhere without them.'* One woman manages using cognitive aspects '*I lead a subcommittee of 10 people – to keep this mind'. I need mints instead of drinking.' 'I make up excuses about going places', 'Grins and bears it', 'I used to get my husband to fetch me if I had an accident. Now I drive myself, which is a big help 'cause I can get to a toilet or whatever'.* Some avoid physical relationships '*Just an absolute no', 'trying to cover the problem up'.*

- **Hopes**

People have hopes for the future *'I would like to get better to I can go out and socialise with friends'. 'I hope there is something which can be done'* was said by a woman experiencing postoperative problems. Other future hopes include '*It would be nice to wear thongs again'. 'It would be nice to stay out and not worry about where the toilets are'. 'I'd like to get back to normal' 'All I want is a good nights sleep'.*

Appendix VIII

SUMMARY OF THE LITERATURE ON EXPERIENCE OF URINARY INCONTINENCE

Harris's review article explores UI experienced by females living in their own homes and its impact on QoL[223]. The authors recognise the importance of developing methods to assess the QoL of sufferers of UI. The authors also conclude that work done on QoL tools is done on the minority of incontinent people who present themselves for help and consequently little is known about the majority unknown to continence services. The author recommends qualitative work be performed on random samples to identify the incontinent population who have not presented for treatment. The authors cite Grimby who found those with UUI had greater feelings of isolation than those with SUI or MUI[160].

Ashworth examined 28 women (aged between 25 and 55 years) using unstructured interviews[27]. This claims to be qualitative research into non-geriatric sufferers of UI. The subjects, recruited by newspaper advertisement, were predominantly women who had not sought help or received intervention. Interviews were conducted in subjects' own homes, audio taped, transcribed and analysed and lasted from 20 minutes to two hours. The first 15 interviews were intensively analysed and the remaining 13 were interrogated for new perspectives and examples of aspects already found. They studied the reasons why they self manage UI and report on coping mechanisms including not recognising themselves as incontinent and concealing their problem. They found the view was often held that UI was associated

with elderly and demented women and this stigma prevented younger women seeking help. They found that incontinence is a socially unacceptable topic of conversation inhibiting their presentation for healthcare. Difficulty recruiting subjects by newspaper advertisement lends further credence to the idea that incontinence is a taboo subject. It is also difficult for sufferers to focus on and think about UI clearly. They found sufferers can react with apathy and the problem is seen as one of personal control. Additionally, the maintenance of normality may involve a great deal of work[27]. There were three main areas to which sufferers paid attention[27]:

1. The vague and difficult to grasp nature of their problem
2. What having incontinence meant for their own self-image
3. The ways in which their life had been affected by incontinence

1. Incontinence is a vague condition, difficult to grasp, a forbidden topic, isolating and illegitimate. Continence is felt to represent self-control and incontinence seems to be a regrettable inevitability with no clear plan of action.

2. Self-image is altered by UI with sufferers hating their bodies and feeling it is their own fault (e.g. for not doing pelvic floor exercises).

3. There is a considerable impact of UI on daily life. The beginning of incontinence is rarely clear. Over time special precautions (such as careful anticipation and mindfulness) become a way of life. Subjects practice obsessive bladder emptying, toilet route planning, checking accessibility of toilets, selecting safe outings or activities, avoiding dangerous movements, strictly regulating fluid intake and

restricting choice of clothing/underwear/shoes. Other practical solutions include buying knickers and pads in bulk for economy, carrying spares, choosing suitable fabrics - cotton, towelling gussets and protecting soft furnishings[27]. Bodily vigilance is also observed with constant self checking for smells and checking with others. Some use vaginal deodorant and deodorised pads. Behaviours for re-establishing normality were reported such as readiness to clear up immediately, throwing slightly soiled underwear away. A sense of sadness and regret for what was lost (e.g. freedom, spontaneity, quality of life) was expressed. Other emotions included dreaded anticipation of worsening in the future. Coping strategies include muddling on with it, minimizing it, renaming it and paying studied inattention to the problem. This means having no strategy to cope but claiming to be satisfied with current coping. Other behaviours include constant avoidances of danger (including being away from home, going for long walks, long journeys, holidays abroad and sex). Maintenance of secrecy was also noted[27].

Clayton used questionnaires and interviews to explore patients' perceptions of their bladder problem, its effect on their lives and the financial costs incurred in managing their incontinence[116]. It gathered information on referral and access to service help, expectations of treatment programs, outcomes they had hoped for and satisfaction with help received. The authors acknowledge there are difficulties in using individual outcome measures when trying to evaluate effectiveness of services[116]. For example, if a patient who cannot go to exercise classes because of embarrassment is then able to go, then that is a success for her. This cannot be a standardised question as many people will not be doing exercise classes in the first place or may still be

embarrassed even if they are cured and illustrates perfectly the importance of capturing the individual perspective. Professionals tend to use measures such as changes in symptoms, cure rates, non-compliance and attendance rates to evaluate services. This work indicates that patients themselves give more credit to impact on QoL, interpersonal aspects of care delivery and organizational aspects of care (access, availability, convenience). Information seemed important to the subjects. Some of the patients' hopes were for information about the causes of incontinence and self-management. Also when asked what would or has made the most difference information was cited[116].

Dowd applied grounded theory to interviews with seven women to understand older women's experience of UI[26]. Results showed that UI threatened their self-esteem and if they could preserve or protect their self-esteem than they were able to lead normal lives. The self-care systems women used to cope were identified but how they developed the systems or sustained them is not clear[26].

Wilkinson explored the perceptions and experiences of UI in six Pakistani women when it was realized they were under represented in their client group[25]. Semi structured interviews were interpreted to reveal the lived experience of incontinence for Pakistani women. Some of the themes were specific to women living within the Muslim ideology but many of the themes may be relevant for the whole population of women suffering UI. They had low self esteem and felt sinful because of their incontinence. Muslim women are obliged to perform ritual cleaning and prayer five times a day. If they pass urine or faeces or are incontinent they become unclean and

prayer is denied until ritualistic cleaning is repeated. The women used prayer to relieve stress resulting from incontinence, but the denial of prayer to them further increased their stress resulting in secrecy and isolation. Three coping strategies emerged:

1. Risk reduction to reduce the number of incidents
2. Management to cope with incontinent episodes
3. Problem sharing with other women

Language barriers made it difficult to seek medical help and to understand advice. Satisfaction with treatment was increased when they were seen by a female clinician and when an interpreter was present. The results were divided into three subsections:

1. Self-concepts and perceptions
2. Living with incontinence
3. Perceptions and experiences of health professionals

1. The primary perceptions of interviewees included low self-esteem, anxiety, loss of self-control and diminished self-concept. Low self-esteem comprised feelings of shame, dirtiness, embarrassment, sinfulness and self-blame. Anxiety encompassed general fear, mental stress, worry of inability to fulfil religious obligations, shame, embarrassment, isolation, fear of not being able to find a toilet quickly, fears for the future, feeling depressed or general worrying. Loss of control resulted in shame, humiliation, fear of ridicule, secrecy and difficulty accepting incontinence[25].

2. Living with incontinence places demands on individuals including interruption of daily activities, risk reduction, incontinence management, sharing problems, marital problems and religious problems (particularly prayer rituals). Interruption of daily activities resulted in modification of the women's lifestyles. Risk reduction included fluid restriction, regular toileting and route planning. Incontinence management includes washing and changing routines and the use of absorbent products. There was a tendency to share problems through talking. Marital relationships were an issue because of poor bladder control during sex. Women would cope by going to the toilet before and after intercourse. Religious problems occurred because of UI interrupting praying also resulting in relationship problems and mental stress.

3. The subjects' perceptions and experiences of health professionals included issues surrounding communication and understanding. Effectiveness was diminished by patients' inhibitions, language limitations and the perception of health professionals as unresponsive. Embarrassment delays presentation. There was a preference to see a female clinician especially if being examined.

The authors concluded, Pakistani women with UI have distinct cultural, language and religious characteristics needing to be understood by health professionals[25].

Krause aimed to determine if the perceived or subjective severity of UI and the expectancy of control affect wetting and also the impact of UI on women's lives[162]. The health belief model (HBM) was the framework used looking at motivation, belief of susceptibility to a problem and belief that compliance would reduce the threat. It

was a secondary analysis of a randomised controlled trial evaluating pelvic floor exercises for SUI. Two hundred and eighty six women were randomised to three groups: a control group, a health promotion group and a PFMT group. Self-reported wetting measures improved with time in all groups suggesting that perhaps health beliefs had influenced improvement[162]. In the secondary analysis women were grouped according to their belief in their ability to regain control and their perceived amount of wetting. The perceived amount of wetting played a stronger role in the treatment outcomes than belief in their ability to regain control. The benefits and barriers to treatment, the expectancy to regain control and the perceived severity of UI may even have more influence on the outcome than the actual treatment itself. The authors conclude that if a woman does not like the type of treatment, does not believe it will help, or does not have time to do the treatment, it is not surprising compliance may be a problem[162]. The findings support the value of individual treatment plans based on individuals' beliefs and lifestyle factors. The role of the nurse in helping to establish what factors of UI are important to the woman will assist in determining the best treatment program. The health belief model and health belief factors provide a potential theoretical framework and a foundation for further research into designing treatment programs[162].

Gallagher examined the experiences of caregivers and recipients to understand events encountered whilst coping with UI in a domestic setting[117]. Four families underwent in depth, semi structured, audio taped interviews. A variety of themes are common between caregivers and receivers such as the struggle to balance self, care

giving and receiving tasks and role expectations. Two main themes emerged from the interviews - coping with care deficits and supporting care abilities.

1.Coping with care deficits had internal and external aspects. Both the caregiver and the care receiver experienced internal aspects. For the caregiver there is a struggle to balance self, care giving tasks and role expectations. For care receivers it involves dealing with the loss of physical capabilities and independence. Care recipients' emotions related to being dependent on others. There is a loss of personal independence and continuous dependence on others for UI management with an inability to maintain personal hygiene and independent toileting activities and an inability to continue with a spousal or parental role. External aspects include financial concerns for caregivers using hired help[117].

2. With regards to supporting care abilities, support is available to caregivers to alleviate or prevent stress when dealing with SUI allowing them to live at home. Care recipients found support through humour, hope, personal motivation, prayer, friendship, physical aid from other people or institutions and spousal support. The results had an impact on nursing practice, education and research. Caregivers offered suggestions for improving management such as physical modifications, and accepting help and finding time away from care giving. Nursing education was highlighted and it was suggested that nurses must teach patients about treatments available for UI and stress psychosocial aspects that can minimise the impact of UI[117].

Horrocks interviewed 20 people over 65 years to explore why community dwelling older people do not present with UI and find ways to assist their presentation[118]. The subjects felt UI was an inevitable part of ageing and they would expect to manage it themselves. People also did not seek advice because of shame, embarrassment and generational differences in attitudes toward disclosing personal matters. Many of the subjects had regular contact with health professionals for other medical conditions but did not seek help for UI. The authors felt that older people may be more likely to seek help if asked specifically about UI by their primary care professionals[118].

Appendix IX

LITERATURE REVIEW OF ASSOCIATION BETWEEN URINARY PROBLEMS AND PSYCHOLOGICAL PROBLEMS

CES-D	Centre for Epidemiologic Studies Depression scale
CCEI	Crown Crisp Experiential Index
DAS	Dyadic Adjustment Scale
DSFI	Derogatis sexual functioning inventory
Ffa	Free floating anxiety
FPI-AI	Freiberg Personality Inventory
GHQ-60	General Health Questionnaire 60
HDHQ	Hostility and Direction of Hostility Questionnaire
HOQ	Hysteroid-Obsessoid Questionnaire
IBQ	Illness Behaviour Questionnaire
ISSI	Interview Schedule for Social Interaction
KSP	Karolinska Scales of Personality
MAI	Middlesex hospital questionnaire (crown and crisp)
OARS	Older Americans Resources Survey
SADS/L	Schedule for Affective Disorders and Schizophrenia/life time version
SDSRS	Sabbatsberg depression self-rating scale
WPSAS	Weissman Paykel Social Adjustment Schedule

Author	Cases	Controls	Tests	Results
Carson[18] [1;181]	56 patients with female urethral syndrome	50000 age matched controls from general medic	MMPI	Significant increase in the tendency to exaggerate symptoms, hysteria, hypochondriasis and schizophrenia

		al patients		
Rees[177;177]	50 patients with dysuria and frequency	Normals come with the EPQ and MHQ questionnaires	EPQ MAI MHQ detailed psychiatric assessments	Patients with recurrent cystitis: More free floating anxiety, obsessionality and somatisation than normals. Normal with regards to phobic anxiety, depression, neuroticism and psychoticism. Same scores as psychiatric controls for hysterical traits. Patients with bladder instability had high scores for free floating anxiety and somatisation. Patients with inhibited micturition had higher scores for free floating anxiety. Bladder outlet obstruction had high scores for free floating anxiety, obsessionality scores higher than psychiatric controls. Very high scores for extroversion and neuroticism. Low detrusor voiding pressure: Less anxious than other subgroups. Obsessionality and hysterical traits were similar to psychiatric controls. Bacteruria had no

				difference to study group as a whole. Dysparunia had high scores for free floating anxiety, obsessionality, hysterical traits and neuroticism. Urge incontinence had higher hysterical traits scores. Depression and hysterical traits increase with age. Young patients with bladder instability had particularly high scores for somatisation.
Stone[178]	18 patients with unstable bladder and failed treatment	None	Psychiatric assessment	All patients had severe life situation problems in the environment and in significant relationships. 15 (out of 18) had partners but were too indisposed by urinary symptoms to participate in sex, 17 patients had chronic depression, 10 patients had functional symptomatology (headaches, backache, gastrointestinal symptoms).
Ferrie[128]	43 patients admitted for bladder retraining	Normative data	EPI	The mean neuroticism score was high. Patients with DO had a higher neuroticism score than those with sensory urgency. Introverted patients do better than extroverts with bladder retraining.

	with medication			
Freeman [125]	57 incontinent women with DO and 22 with USI	Published normals. DO and USI groups were compared	HOQ CCEI hysteria subscale and depression subscale HDHQ EPI neuroticism subscale Zung self rating scale	DO women were higher than published norms for obsessionality, somatic anxiety, depression hysterical personality traits. Lower paranoid hostility in the DO group than normals. DO women were higher than USI for free floating anxiety, phobic anxiety, neuroticism, hostility and depression.
Morrison [114;120]	165 patients (226 patients awaiting	50 patients awaiting	EPI	Significantly higher than normal neuroticism scores for all patients referred for bladder investigation. No higher in patients with DO than in the group as a whole.

	urodynamics, 61 were excluded as high lie scores) 115patients urge incontinence	urodynamics who did not have the diagnosis of urge incontinence		Neuroticism score was not related to treatment response.
Macaulay[120]	211 patients attending urodynamics (106 of 317 excluded as unable to	Normative data from questionnaires on normals and psychi	VAS of troublesomeness, Spielberger stait/trait anxiety inventory, Wakefield	Significantly more anxious than normal population. Patients with DO or sensory urgency are significantly more anxious than patients with SUI or general medical inpatients. Anxiety scores were similar between patients with SUI and general medical inpatients. Urodynamic patients were more depressed than normals but not as depressed as psychiatric inpatients.

	complete questionnaire)	atric inpatients	depression scale, CCEI	Depression scores were higher with DO than SUI. All groups had higher than normal scores for phobic anxiety and functional somatic complaints and hysteria
Norton[12] [7;127]	102 patients. 117 patients attending urodynamics 33 had DO, 45 had USI. 27 had normal urodynamics. 12 were excluded (no urodynamics, no	Normative data from questionnaires on normals and psychiatric inpatients	Present state examination EPI STAXI Psychiatric history	No significant difference between DO and USI groups. Patients with no detectable abnormality on urodynamics showed high scores within the range for psychiatric outpatients.

	notes or voiding disorder)			
Walters[1] [79]	63 patients with urinary incontinence 35 had USI 28 had DO (of whom 9 had MUI)	27 continent patients from gynaecology and menopause clinics	MMPI Uplift and hassle scales Sexual dysfunction screening questionnaire	No difference between USI and DO groups. Subjects with DO scored higher than controls for hyperchondriasis, depression and hysteria. Significantly abnormal MMPI profiles were found in 86% subjects with DO, 69% subjects with USI and 37% of continent controls. DO group had a lower frequency of uplifts and greater intensity of hassles than continent controls. Both incontinent groups had more sexual dysfunction than controls and there were no differences between the 2 incontinent groups. 68% women with USI and 34% with DO said urinary symptoms interfered with sex.
Morrison [126]	169 patients with		GHQ-60 WPSAS 43pts	47.9% had significant psychiatric morbidity

	bladder dysfunction		had SADS/L	
Lagro-Janssen [182]	110 women presenting to GP with incontinence, 66 USI 20 MUI 18 DO 6 had no incontinence demonstrated	Groups without DO used to compare to group with DO	Health locus of control Psychometric Mental state VOEG (measuring somatic and functional complaints due to stress). An anxiety scale Self rating	No difference between patients with DO and other types of incontinence

			scale of Complaints	
Berglund[183]	45 SUI women who were candidates for surgery (selected from 162 women attending gynae outpatients c/o urinary incontinence)	50 women attending for routine gynae check up. All were continent	KSP EPI BDI ISSI	Incontinent for more than five years had higher somatic anxiety, psychic anxiety, psychasthenia and suspicion than continent controls. USI patients had higher somatic anxiety, psychic anxiety, muscular tension, psychasthenia and suspicion compared to continent controls on KSP. On EPI only lie score was higher than controls. Those who were improved/failure one year after surgery - high degree of neuroticism, low extraversion, high somatic anxiety, psychic anxiety, psychasthenia and suspicion compared to cured women. The improved/failure women had a low level of social integration compared to cured women. Predictors of surgical outcome for SUI are duration of SUI, neuroticism and age.
Drutz[184]	100 patients		STAXI MMPI	The whole group had higher than normal anxiety levels.

	referred with persistent lower urinary tract problems. 25 SUI, 18 OAB, 6 SU, 34 MI, 17 ESS+DSD			There were not differences between urodynamic subgroups
Chiara[185]	87 patients 104 referrals 10 excluded and 6 withdrew) 58 SI, 19	none	STAXI CES-D IBQ	Patients with DO showed more inner anger and anger trait than SUI or MUI. The conviction of illness was greatest in SUI and MUI. Irritability and general hypochondria was greatest in those with DO.

	MUI, 10 DO			
Bodden-Heidrich[1] [86]	72 patients having urogynaecological assessments: USI 43%, DO 10%, MUI 6%, No incontinence 41%	34 patients for cancer screening - no urogynae symptoms	Personal and medical history FPI-A1 STAXI BDI	Clinically incontinent patients were more compliant, more moderate, more withdrawn, less critical, more anxious and had higher inner anger than normals. Patients with USI were more anxious and more withdrawn. Patients with DO had greater willingness to direct anger inwards than normals.
Yip[21]	91 patients with urinary symptoms. DO 29, USI 36, normal urodyna		KHQ DAS DSFI	USI or DO had poorer QoL, poorer marital relationship and less sexual satisfaction despite having no change in sexual drive. DO women had higher scores in the emotions domain. USI and DO women had higher severity measures scores than the normal group and lower scores for marital relationship. Also lower sexual

	mics 26			satisfaction but same libido.
Heidrich[1] 80	103 patients over 60 years with chronic illness. Women with UI compared with controls	Women without UI	Symptom scale OARS – schedule of illnesses, OARS ADL measure. A symptom bother scale. Scales of psychological wellbeing. Neugarten's Life Satisfaction Index	UI scored significantly lower than those without UI on purpose in life, autonomy, and affect balance. UI had significantly lower self-esteem than without UI. More bother from symptoms including aching, stiffness, tiredness, pain, breathlessness, itch, weakness, and concentration/memory problems.

			A Affect Balance Scale Rosenberg's self esteem scale. CES-D Jackson Personality Research Inventory	
Das[123]	89 people with refractory urge incontinence, nonobstr	Before and after treatment with sacral nerve	Beck depression index, medical outcomes study	Before treatment there were detectable levels of depression and reduced QoL. Three months after the implant QoL and depression improved. The delayed treatment group had a worsening of their depression and QoL.

	uctive urinary retention or urgency frequency	stimulation. There was also a group whose treatment was delayed.	short form 36	
Lin[187]	106 women with urinary incontinence	Women with high incontinence impact were compared	Incontinence impact, symptom distress, treatment-seeking behavio	Incontinence impact correlated with symptom distress. Women with high incontinence impact and symptom distress were more likely to seek treatment than those with lower impact and symptom distress.

		to those with low incontinence impact	ur.	

Appendix X

PSYCHOLOGICAL INTERVENTIONS AND EVALUATION OF INTERVENTIONS USING PSYCHOLOGICAL TESTS

Author	Cases	Controls	Therapies evaluated	Outcome measures	Results
Hafner[10;10]	26 patients of 31 with UI	None	Psychological treatment (group and individual)	Degree of improvement of symptoms	Patients grouped into most neurotic and least neurotic groups. Most neurotic responded better to treatment and reduced their MHQ scores
Obrink[191]	12 patients with symptoms and/or signs out of 33 patients	21 women with no symptoms or signs	Puboccygeal repair	EPI SDSRS	Controls were in the middle for neuroticism and depression scales. Patients with symptoms but no signs had high neuroticism and depression scores. Patients with signs but no

	who had pubococcygeal repair for USI 10-20 yrs ago. Six patients had symptoms but no signs. Three patients had signs but no symptoms. Three patients had symptoms and signs				symptoms had low neuroticism and depression scores
Freeman[20]	50	Patients	Hypn	Cystomet	29 patients symptom free,

	patients with DO	acted as their own controls between assessment and treatment	othera py	ry Frequenc y volume charts Symptom s.	14 improved, seven unchanged. Cystometry- 22 patients stable, 16 improved, six no improvement
Ferrie[128]	43 patients complete d EPI. 30 patients had EPI and cystometr y 65 patients urge incontine nce (66% had cystometr		Bladd er trainin g- inpati ent	66% complete d EPI	88% patients improved on hospital discharge. Fell to 57% at three months and 38% at six months. Neuroticism scores between responders and non-responders were not significantly different in patients completing EPI. Patients with DO on cystometry who completed EPI (n=17) showed no significant difference between responders and non-responders. Introverted patients responded better to

	y)				bladder retraining. Discussion suggests that introverted patients with low neuroticism scores may respond better to inpatient bladder training
Macaulay[11]	50 patients with DO or SUI. Randomly allocated to therapies		Psychotherapy (10 patients with DO, nine patients with SUI) Bladder training (eight patients with DO,	Bladder diary Mental state VAS of symptoms STAXI Wakefield depression scale CCEI	<u>Psychotherapy group</u> Improvement in nocturia, urgency, incontinence <u>Bladder training</u> Improved mean detrusor pressure rise, first sensation, state anxiety, depression, urgency, nocturia, incontinence <u>Propantheline</u> Improved frequency, state anxiety

			eight patients with SUI) Medication (propantheline) (eight patients with DO, seven patients with SUI)		
Morrison[114]	165 patients attending urodynamics		EPI applied initially and after treatm	EPI	53% patients completing the questionnaire responded positively to therapies. 25% patients lost to follow-up. No difference in neuroticism scores between

			ent-medical and 'other'		successfully treated group and others. No difference in neuroticism scores for pharmacological treatments as opposed to other treatments
Rosenzweig[192]	63 patients with USI	Group split into successful and unsuccessful treatment (subjectively and objectively)	USI surgery	Subjective cure Objective cure (urodynamics) Questionnaire on symptoms and psychological status	Patients with successful surgery had improved psychological status. Patients with unsuccessful surgery had increase in depression
Lee[32]	101 patients with incontinence	No treatment. Population	Behavioural and educational	YIPS Aids to living scale IIQ	Reduced incidence of incontinence in treatment group. 16% treatment group cured, 41.5% improved. YIPS indicated

	34.7% SUI 37.6% UUI 22.8% MUI 5% other forms of incontinence	randomly assigned to case or control	measures	Self perceptions of symptoms and overall health Bladder chart	that the treated group were better able to cope with their incontinence than the controls
Berglund[115]	45 patients awaiting surgery for SUI	50 healthy women attending routine gynae check up	Retropubic urethrocystopexy or puboccoccygeal repair (taken together as one	KSP EPI BDI ISSI	Patients with failed surgery had more neuroticism, less extroversion, higher somatic anxiety, psychic anxiety, psychasthenia and suspicion and lower levels of social integration. Duration of SUI and degree of neuroticism predicted outcome to surgical treatment in 80%. Women objectively cured had a decrease in

			group)		neuroticism one year after surgical treatment. Women objectively cured had lower BDI scores before and after surgery. Women with failed surgery had lower availability of social integration and adequacy (ISSI)
Garley[19]	10 women with UI	None	CBT	HADS I-QOL Bladder function records	No change in anxiety or depression, improved incontinence related QoL, modest improvements in bladder functioning
Das[123]	89 people with refractory UUI, non obstructiv e retention or frequenc	Delayed treatment	Sacral nerve stimul ation therap y.	BDI Medical outcomes study SF-36	Detectable levels of depression and reduced QoL at baseline. Improvement in QoL and depression three months after implant

	y				
Burgio[67]	197 women over 55 years with persistent UUI	Placebo controlled group	Group 1. Biofeedback assisted behavioural treatment. Group 2. Drug treatment (oxybutynin). Group 3. Placebo	Hopkins symptom checklist	All groups improved on the nine subscales and the global severity index. Trends suggested that behavioural treatment tended to produce the largest improvements. Reduction of distress was not correlated consistently with reduction of incontinence
Kelleher[122]	1077	Placebo.	Tolter	Short	Continued treatment with

	patients with OAB with incontinence		odine.	form 36 KHQ.	tolterodine provided additional benefits in QoL on KHQ, particularly psychological aspects
Lamb[44]	174 women with stress and/or urge incontinence	Other treatment group	Group 1 – group treatment physiotherapy. Group 2 – individual physiotherapy	Symptom severity index, incontinence related QoL questionnaire, NHS costs, out of pocket expenses	More women expressed and initial preference for individual treatment. No difference in symptom or QoL outcomes between group and individual treatment. Group treatment is less expensive
Tadic[45]	42 women over 62 years		Biofeedback	Urge impact scale (URIS-	Biofeedback improved UI and psychological burden especially in those with a history of depression

	with urge UI			24), three day bladder diary, Mental component subscale (MCS) of SF-36	

Appendix XI

FOCUS GROUP

XI.I Topic guide

XI.II Results

XI.I Topic guide

1. About the service provided by your GP:

How long did you have symptoms before you saw your GP?

What did your GP do in response to your symptoms?

How long did you wait for a referral to hospital?

What would you have liked to have happened at this stage?

2. About the investigations (tests) you had:

Did you have sufficient information/explanation about any tests?

What was your experience of the actual procedure?

How did it make you feel?

What would you have liked to have happened at this stage?

3. About your diagnosis:

When were you informed of your diagnosis?

Who by?

What advice did you receive?

Were you given any information or contact numbers?

What would you have liked to have happened at this stage?

4. About the treatment (surgery, physiotherapy, urodynamics…)

What was the treatment like?

What about the information you received?

Do you feel it was sufficient?

Did you understand it?

What would you have liked to have happened at this stage?

5. About follow up care:

Who provided your follow up care (consultant/GP/nurse/other)?

Where was follow up care provided (at home/hospital/outpatient clinic/GP surgery)?

How often did you receive follow up care (six weeks/six months/annually)?

Did you feel this was appropriate (would you have liked more or less follow up care)?

Did you have access to support? If yes, who from? What would you have liked to happen at this stage?

6. Have you any suggestions for improving and developing future urogynaecological services?

XI.II Results

- **Origin of Urinary Continence Problems**

The group discussed how and when their continence problems first began. Four participants described how they considered incontinence to be an unwelcome but expected part of the ageing process, two commented how symptoms had occurred following gynaecology surgery and one participant believed on reflection her continence problems arose as a result of childbirth. Participants described how they had waited between six months and '*over ten years'* before seeking advice. Another woman described how she initially thought her symptoms had been present for about six months before she sought treatment, but with hindsight now believes she had probably been ignoring the signs for years. Reasons for delay in seeking help or advice included:

- A reluctance to accept it was happening to them
- An unwillingness to discuss an *'embarrassing and personal'* problem – particularly with a male general practitioner
- Feelings of shame and guilt
- Lack of knowledge about where and how to seek help
- An assumption that nothing could be done to treat incontinence
- An assumption that incontinence was something to be tolerated in old age
- A misconception of the benefits of pelvic floor exercises

- **Symptoms**

When discussing their experiences of UI group described various symptoms. One participant discussed how she continuously refused to believe she was incontinent

and described her feelings: *'I couldn't think I could be doing it (wetting herself). I kept thinking it might be an infection – it might be a psychological problem.'*

- **Pelvic Floor Exercises**

A number of the women told how they were advised to undertake pelvic floor exercises following childbirth, but were unaware or ill informed of the purpose or benefits to be achieved.

- **Seeking Help – who and how?**

One participant described how she eventually saw her GP and was relieved and reassured that '*it…* (incontinence) *wasn't her fault'.* Following a physical examination her doctor informed her she had a prolapse and subsequently referred her to hospital for treatment. One woman explained how she became severely depressed after enduring symptoms (including pain) for eight years. She was reluctant to consult her male GP and believed the female GP in the practice was difficult to get an appointment with. She commented she only began to feel better once she was able to talk with another patient who she felt really understood her experience.

Another woman expressed how reluctant she was to seek help, how she persistently denied and ignored her symptoms, until in desperation she eventually contacted a national telephone help line. They confirmed the symptoms she described suggested she *was* incontinent and advised her to see her own doctor. She went on to discuss what happened when she finally consulted her GP. She explained her GP had *'very little knowledge*' of incontinence and he referred her to the practice nurse. One

participant informed the group she *'first plucked up courage to do something'* when she saw an advertisement by a private drug company, seeking volunteers for research into incontinence and contacted them to find out more.

- **Information – what and when?**

The group described how they believed previously there was very little knowledge or understanding of continence issues in the public domain, but more recently, publicity campaigns in the media have raised awareness. The group discussed how little publicity surrounding continence issues appears to come from the NHS or public funds – they felt the majority of publicity related to sanitary products (pads) and were likely to be funded by private companies manufacturing sanitary products. One participant described how an incontinence article had prompted the first frank discussion with her husband regarding her continence problems – and served as a catalyst to book an appointment with her GP. All participants agreed that at the onset of their problems they were unaware of any specialist continence services within their area.

- **At the hospital**

The group discussed their various experiences of diagnostic tests and the importance of language used to explain symptoms and procedures. One woman described what happened prior to her initial hospital consultation. One participant revealed that she had been apprehensive about the procedure, but felt she received a comprehensive explanation and was therefore quite relaxed during the examination. She described

how she was intrigued to discover what the examination involved and was *'happy about it'.*

Another participant expressed how she felt when she underwent a similar procedure at another hospital more than ten years ago. She found it humiliating, degrading and absolutely awful. She explained how some years later she was advised to undergo the procedure again. She informed the consultant of her previous experience and explained her fear and reluctance to repeat it. The consultant reassured her *'things have moved on',* and although she had her doubts and was '*absolutely frightened and scared'*, she agreed to undergo the procedure again.

Another participant described how a diagnosis of a further medical problem resulted in a contra-indication for her continence treatment. She used an alarm clock to manage things at nighttime herself. The group was intrigued to hear about this and congratulated the woman on her successful attempt to reduce the nocturnal occurrence of incontinence without the use of medication. This participant described how her achievement had made her feel *'ten years younger.'*

Three participants discussed their inpatient stays. One felt it was marvellous as there was a lot of discipline to help the information sink in. Another participant confirmed she too had been admitted to hospital for one week for intensive bladder training and education and commented that is was wonderful. One participant described how she had been attending hospital two or three times a year for more than seven years.

- **Terminology**

The group liked the down to earth terminology the nurses employed – like calling urine 'wee'.

- **Treatment**

One participant commented that the information she received had been '*very, very good'* and easy to understand. She was able to ask lots of questions and felt that following one week's intensive treatment as an inpatient she was more informed and understood much more about her own anatomy and physiology. Another participant commented she too had found the week she spent as an inpatient particularly good – describing it as helpful and informative. Other participants had also experienced this intensive, focused inpatient treatment, describing having their fluid balance measured and monitored. They particularly appreciated not being confined to a bed or ward with the freedom to come and go as they pleased. Others in the group who had not experienced this kind of treatment were very interested to hear about it.

One participant described how she was initially offered surgery (at another hospital) to treat her symptoms. She explained how the consultant had spent time discussing the possible risks of surgery, but no side effects were anticipated in her case. She experienced significant problems post-surgery but remained positive about the treatment. Another participant had also experienced significant problems post-surgery. She informed the group she was originally admitted for routine gynaecology surgery – during surgery her bladder wall was cut and she commented, *'when they*

did it (a hysterectomy)…they cut my bladder…they told me. It was an honest mistake…'

One woman commented how she was offered physiotherapy and pelvic floor exercises to treat her incontinence. However, she explained at the time she did not fully understand the information that arrived with her initial appointment letter and as a result she perceived she would be participating in group exercises in a gym, requiring special clothes.

The group discussed coping mechanisms for managing incontinence and agreed they no longer expected a complete cure, but aimed for a degree they could comfortably manage. One woman voiced her fears about telling the nurses she had experienced a setback – and worried in case she would be discharged because she had exhausted all her treatment options. As a group, the women vehemently denied this would be the case and one commented *'She* [nurse] *won't … she'll offer some other… she'll say well let's up the dose of what you're taking, or let's try something else… you don't feel like you're going to be pushed off like I feel in some other hospitals.'*

The woman was encouraged by the groups' comments and belief that staff would not *'give up with you'.* The group also offered advice about what to drink and what to avoid, and advised the woman to bring a piece of paper to her next appointment so she could write down any information or instructions given by staff. One participant explained how prior to her initial appointment at the hospital she had been unaware

of any existing treatments for incontinence. She believed there may have been something available for younger people who had suffered either from birth, or as a result of giving birth, but believed for older people it was something that had to be endured rather than cured.

- **Information and environment**

Generally, the group believed the tests should continue to be carried out in a hospital environment because *'they've got all the equipment.'* All participants agreed they welcome the fact that Birmingham Women's Health Care is an NHS Trust specifically designed to meet the needs of women. A feature they particularly appreciate is that urogynaecology services at the hospital are discreetly sited alongside other services and therefore it is not overtly apparent that women are attending the *'waterworks clinic.'*

The group discussed how they accessed information about continence issues. One woman describing how she made several telephone calls to commercial manufacturers of continence products and national help lines in order to try and find out more. Another participant commented that there was very little information available in her local GP practice. The group felt the lack of information was a result of under-funding and the only publicity promoting continence awareness appeared to be supported by the commercial sector. The group agreed that incontinence could lead to other issues e.g. depression and breakdown of familial relationships, and acknowledged this had cost implications i.e. the need to access medicines and seek psychiatric support.

Following on from this discussion, the facilitator asked the group to consider the scenario of unlimited funds available for continence services and asked how they would allocate it? Their suggestions included: *'Information as much as anything… I didn't know there was help there…'*

All agreed they would expand the amount and availability of information related to continence issues and promote the available services wherever and whenever possible, using different venues to increase awareness. The group discussed the most appropriate place to site information and considered doctors' surgeries a suitable place. However, one participant felt she would be embarrassed to pick up a leaflet about continence issues – even in a GP surgery. One participant considered access to continence leaflets sited within the doctor's examination room might provide the impetus for an embarrassed patient to raise the issue. Other participants discussed how they had accessed information leaflets from the hospital clinic and the public library. The group also discussed the possibility of using advertising boards in supermarkets to post flyers and information.

One woman informed the group what happened when she sought advice from her local pharmacy: *'I went into the chemist… and it had to be a man as well! And I actually told him – you know… he was very, very good. He advised me on the pants and pads and everything'.* The group felt the content of information leaflets should include contact details for local services or a telephone number where people can

access continence advisors and discuss their continence issues. The group felt current information leaflets were generally aimed at advice about which pad to use.

- **Continence Products**

The group discussed their initial lack of awareness of the availability of continence products such as pads, and how they struggled to cope with incontinence using sanitary towels: *'…when you didn't know about them (incontinence pads)... you're lining your knickers with several ordinary sanitary towels ...and making sure they're all tucked in…'* The women described how they felt self-conscious because of the 'bulkiness' of sanitary towels beneath their clothes.

- **Living with Incontinence**

The group discussed the impact and influence incontinence had on their self-image, confidence, social life and other members of their family. They all agreed they were initially reluctant to accept they *were* incontinent, unwilling to acknowledge or discuss it with anyone else (even partners) and were very distressed and embarrassed by the symptoms they experienced.

- **Personal Hygiene**

One woman explained how during the course of her daily working life she visited many people in their own homes. She described how she became acutely aware of a strong odour of urine emanating from some of the homes. Some participants worry about their own smell *'Yes... I think it's one of those things we do think. When we do have an accident… you think everyone can smell you and you get that strong smell… you do feel*

extremely embarrassed.' One woman recalled her tale for the group, she laughed at her predicament. This pattern of using self-deprecation and humour to describe themselves or events related to their condition was often apparent within the group and appeared to be a method some women used to cope with their situation.

- **Relationships**

The women described the psychological impact incontinence had on their lives. They also discussed how this affected their relationship with partners and other family members, and the way these relationships changed once they had more information and accepted their diagnosis. Another participant described how she believed getting treatment for her incontinence had actually saved her marriage. At the onset of her incontinence she tried to ignore the symptoms and denied she had a problem. However, she insisted on separate beds for herself and her husband because she was ashamed and embarrassed – she believed she had a strong, unpleasant odour and constantly washed and showered to try and eliminate it. She confided how she didn't want her husband to come near her because of the perceived odour – she thought her husband must have noticed it, but this was something so personal they never discussed it. However, since coming to the hospital she felt quite comfortable discussing her continence problems with her husband – and feels she is very lucky that she *'eventually took the bull by the horns*' and sought help.

- **Follow Up and Discharge**

One woman described how she regarded continuity of care as a very important aspect of treatment, necessitating development of a good relationship with clinical

staff. The group agreed that over time they had cultivated good relationships with clinical staff, particularly nurses, and felt this was possible because they frequently encountered the same staff at each visit.

- **Patients' Support Group**

Participants who had attended the support group all spoke positively about the benefits this had afforded them. One woman described how her husband encouraged her to overcome her initial reluctance and attend the support group. She was surprised by the number of people affected by incontinence, and commented her attendance at the group made her realize she did not have to endure her problems in isolation. She discovered a further benefit of the support group was the opportunity it provided to discuss her concerns with her husband by sharing what had been discussed at the support group. One woman described how she believes the patients' support group is so good she would like to see it expanded to cover other local areas at times to meet the needs of people who are currently unable to attend. She explained how it had helped her: *'I've been glad to meet other people and be able to discuss it and not feel embarrassed about it'.*

Others agreed their membership of the patients' support group had helped them to bring the issue out into the open with their partners and families. It was also a relief to be able to discuss the subject candidly and know they were not the only person experiencing incontinence. The women explained the support group also has an educational element to it as guest speakers are invited to meetings to talk about various topics of interest to the group. One woman commented on how helpful she

had found the support group and her only regret was that if she had known such support existed she may have sought help earlier.

- **Discharge**

The women voiced different opinions about being discharged from the hospital. Some saw it as a cause for celebration – a sign they had achieved success and were managing their incontinence. One woman explained how she currently attends the nurse led clinic every six months, and feels it is a crutch she can lean on – knowing she hasn't been completely discharged and will be coming back to clinic again. Other participants discussed how they viewed discharge with a sense of trepidation – they were fearful of what would happen if their problems surfaced again some time after discharge and how long they might have to wait before referral to hospital.

Participants who had been discharged attempted to reassure those who dreaded it. The woman explained nurses had given her a direct telephone number and advised her she could use it at any time to contact them if she was worried or wanted to discuss any continence issues she might have. She commented the nurses had inspired her with confidence in her own ability to manage, and at the same time had reassured her she could contact them if necessary. Other participants discussed how they were relieved to discover they could contact clinical staff directly if they had a problem following discharge. They worried they would have to go back to their GP and begin a protracted referral route again.

Another woman expressed her worries explaining that her perception of discharge meant severing all contact and if she had a problem following discharge she would be reluctant to contact the clinical team directly for fear of disturbing a busy clinic. Another participant also commented she would be quite reticent to contact staff directly following discharge, but also worried that she may have to wait a long time for referral back. Following discussion with other women in the focus group she commented they had allayed her fears to some degree, because she now understood she had a *'lifeline'* – the direct line for clinical staff.

- **Concluding remarks**

The facilitator asked the group whether they had any further topics they wished to discuss during the closing stages of the focus group meeting. The women commented they had enjoyed the focus group meeting and considered it a further welcome opportunity to discuss their issues with people who had similar experiences. There were also many positive comments about the staff, the Trust and the patient support group.

- **Recommendations**

From the focus group discussion and the subsequent transcription notes the following local conclusions were drawn:

1. To raise awareness of continence issues within the public arena through increased publicity and media campaigns
2. To increase the availability of information about continence services and how to access them

3. To increase the amount of information relating to continence services
4. To increase accessibility to continence services
5. For GPs and GP practice staff to consider continence during routine consultations
6. To receive clear explanations in different formats – verbal, written, etc.
7. To be treated with dignity and respect in an environment conducive to preserving confidentiality
8. To be given enough time during consultations to digest their diagnosis, ask questions and understand treatment implications
9. To have as much information as possible about treatment options to support informed choice
10. To have direct access to specialist clinical staff – i.e. telephone consultation and advice following discharge
11. To have equitable access to free continence supplies
12. To preserve and expand the patients' support group
13. To link these recommendations to the aims of the continence care pathway

Appendix XII

SUMMARY OF STUDY GROUP 3 CASE STUDIES

A group of women who were scheduled to undergo stress incontinence surgery were interviewed. Before their operation they underwent the following:

1. A repertory grid about how they are at various time periods related to their bladder and operation
2. A repertory grid about things they like or enjoy and things they do not like or enjoy and why
3. A list of situations affected by incontinence and situations less affected by incontinence and questions of pad use
4. The Kings Health Questionnaire (KHQ)
5. A general interview
6. Urodynamics

Postoperatively each woman underwent the same assessment plus several questions on visual analogue scales (VAS) about their treatment, mood and leakage. In addition their original interview was scrutinised and they were asked direct questions relating to their preoperative interview. This was done at the end of the interview to avoid influencing the preceding responses. Woman were then asked if they would encourage a friend to have the operation and what the best and worst thing about the operation were.

There were 22 women recruited to this group. Several of the women did not undergo surgery for various reasons and several did not attend for their full assessment. The results are fourteen case studies on those women who had full evaluations.
Twenty-two women were interviewed who were scheduled to have SUI surgery. They underwent a pre-operative interview, repertory grids, situations affected by incontinence list, pad use question, KHQ. All had preoperative urodynamics as part of their clinical care and these results were retrieved from their notes. Postoperatively women had the above measures performed plus a VAS about their surgical outcome and postoperative urodynamics, which would not be a usual part of their clinical care. Points in their pre-operative interview were specifically addressed at the end of their postoperative assessment. Eight women were excluded for the following reasons:

- Not having operations with in the timescale of the study (four cases)
- Failure to attend the postoperative interview (one case)
- Cancelling surgery to attend physiotherapy (one case), or because of DO (one case)
- Time constraints (one case)

The remaining 14 women's pre and postoperative assessments are presented as case studies. Two of these women declined postoperative urodynamics but were included as they completed all the other assessments.

Case Study 1

Preoperative repertory grids

Preoperatively she felt awful, depressed, uptight, embarrassed, had difficulty shopping and problems with walking. She both hopes and expects to be not awful, feel lovely, not uptight and be able to walk and shop with no difficulties.
She enjoys crossword puzzles, knitting, cooking and to less an extent gardening. Most of these hobbies make her brain work and make her feel relaxed, not upset and involved. She does not like rude people or war and she does not enjoy these and finds them not relaxing, upsetting, she is not involved, they don't make her brain work and are not hobbies.

Preoperative situations affected by UI

The situations where her incontinence causes her the most difficulties are walking, in company, having to look for toilets and when she goes out for a meal. Her incontinence is less of a problem to her when sitting down. She uses about three Tena lady max/med or Tena lady pants activity per day because she is incontinent.

Preoperative interview summary

This lady had a hearing impairment and her husband was present for the interview at her request. Her bladder problems got gradually worse about three years ago and she gave an example on holiday where she had a wet patch on her skirt from leakage and someone commented that she had sat in something. She was embarrassed and had to sit on a plastic bag in the car and now takes towels and spare clothes with her. She feels she is spoiling other people's enjoyment. She describes urgency during cooking with UI and comments that her washing machine is on all the time. She has concerns about smell and asks her family about it.

She went to her doctor who referred her to the nurse who told her about an operation and made her an appointment. She attends the practice nurse with a hormonal ring and she mentioned an operation like a hammock.

She describes an internal procedure at the hospital but does not know what it was, possibly physiotherapy, but she thought it was not very nice. She went several times. Then an appointment was made for the urogynaecology department where the nurse told her she didn't know if there would be an operation and asked Mr (urogynaecology Dr). The nurse put her at ease. She was aware that there are two operations and she felt that the one she is going to have isn't as bad as the other one but she heard a lot of good reports.

She is expecting to do a lot of things after the operation. She said she is not ill but she feels depressed and stressed with it. She said *'I really don't know how I am. Just leaving it to the Gods to do the trick and make life a lot easier'.*

She commented that she hadn't felt embarrassed during the interview.

Urodynamics

Preoperatively USI was demonstrated. She had urgency symptoms and also had ambulatory urodynamics preop, which did not show any DO but confirmed USI. Postoperatively there was no USI. She had DO at capacity with a large leakage and a slow void.

Kings Health Questionnaire

Domain	Preop Score	Postop Score
General Health Perception	0	0
Incontinence Impact	100	0
Role Limitations	100	0
Physical Limitations	83.33	0
Social Limitations	100	0
Personal Relationships	0	0
Emotions	100	0
Sleep / Energy	33.33	66.67
Severity measures	100	0

Assessment of subjective success of surgery for stress incontinence (VAS)

She feels her operation was successful (9.95 where 0 is not successful and 10 is completely successful). She is completely satisfied with the outcome of her operation (10 where 0 is not satisfied at all and 10 is completely satisfied). She was very happy at the time of the interview (10 where 0 is very unhappy and 10 is very happy). She felt very relaxed at the time of the interview (0 where 0 is very relaxed and 10 is very tense). She never leaks (10 where 0 is leak all the time and 10 is never leak).

Postoperative repertory grid

In general how she is in reality is very close to how she hoped to be and better than how she expected to be. She hoped to not need pads, enjoy shopping, participate on holiday and not to have leakage and these have happened. In particular she is able to walk and she could not do that before surgery.

She enjoys going out for meals, knitting and puzzles. She does not like bombings, rude people and not having a car. She forms one of six constructs around her ability or inability to do these when leaking. Leaking does not fit in well with all the elements but may show that she still thinks about the bladder. The other constructs relate to whether the element involves going outside, whether she has to rely on others, whether it is a hobby and whether she sees it as safe and enjoyable.

Postoperative situations affected by incontinence

Postoperatively she was asked in what situations her incontinence causes/caused her the most difficulties. She does not have UI now and these relate to her memories of before the operation. She had more difficulties when she was out anywhere, visiting people, walking and she didn't enjoy her holidays. It was less of a problem staying at home. She no longer wears pads or any extra protection.

Postoperative interview summary

She said that since the operation things have been excellent and she will never be able to thank her surgeon enough and said that she had written a letter. She said he was a nice man and doesn't talk down to her. She felt she had excellent care in hospital by the doctors and nurses. She commented that you hear bad things but she

could not fault them. She had a catheter in overnight and wasn't in hospital for very long. She was not sure if her ring had been changed or not during surgery. Her practice nurse examined her after a month and said it was not there and this made her feel a lot better.

She feels that everyday life is absolutely great. When asked if anything had changed she said it had not really, apart from feeling better in herself, not feeling dreary and dirty.

She gave an account of before the operation when she was doing something with her husband in the kitchen, the phone rang and she had to rush to the loo. She also mentioned that it used to be like a race to get to the toilet and if he got there first she would be dancing about and have to change three or four times.

She has told her granddaughter that she is dry, who got on the phone to her mum who said *'oh, we'll give you five stars'.* She thought this was amusing. All her family knew about the bladder problems and were very helpful and supportive.

The preoperative interview was analysed for concerns and issues and these were then posed directly at the end of the interview to see how or if things had changed.

1. Are you still feeling aware, in case of being wet?

No

2. What about carrying spare clothes and towels?

No

3. What about not reaching the toilet in time?

No problem

4. Is the washing machine still always on?

No. That's another thing I'm saving on

5. What about worrying about smelling?

I do still ask if they can smell me and they say they couldn't even smell me before

6. Do you still experience embarrassment over the bladder?

No

7. Are you able to do a lot more things now?

Yes, 'cause I haven't got it on my mind.

(What kind of things?)

I can't think of any. Going down the garden, fetching something from the shed, hanging the washing out. My husband used to do all that.

8. Do you still feel depressed and stressed out?

No

9. Is life a lot easier since your operation?

Yes

(What is the best thing about your operation?)

Made life easier

(Worst thing)

Can't say there was a worst thing, apart form leaving my husband at home. They brought me in because I'm deaf to get me used to the ward. That's another thing they were very kind about.

(Are you glad you had your operation or do you regret it?)

Glad. The nurse (at the GPs) was really chuffed. It was her that told me. She said *'I hope I don't see you again'* and asked if I'd had I flu jab. I told her I was having it next week but she gave it to me then so she wouldn't have to see me again.

(If a friend told you that she was going to have this operation what would you say to her?)

I'd tell them to go ahead and have it.

I have some puzzles magazines, chat and take a break. There was a letter from a lady who had this. She was younger than me. I can't begin to tell anybody what it's done for me and I'm a lot older. You don't stop to think other people are having it. I find when I go to the loo it take me longer.

Case study 2

Preoperative repertory grids

She would like to be able to have a good laugh, which she cannot do at the moment. Her hopes and expectations for after surgery are the same and these are not to be leaking, worried, embarrassed, not made fun of, not expecting to leak and not having to wear pads all the time. All of these things were happening preoperatively. In relation to feeling worried and embarrassed she is actually expecting that these will be even better than before the bladder problems started.

She enjoys going out with friends, listening to music and cake decorating and finds them enjoyable and relaxing. Some of them are solitary and some in company and this was one of her constructs. She does not like rude people, jumping out of a plane and rain. They do not make her feel good and are not pleasurable or fun. She did not use UI in her construct development.

Preoperative situations affected by incontinence

She is affected by UI in exercise classes, when she has a cold, and is coughing and sneezing. She won't try anything new in case toilets etc are not close to hand and feels excluded from fun and is affected when she laughs. She also feels self-conscious when wearing trousers with pads

UI is less of a problem at home, when there's not much fun happening, if she is around people she knows. She wears up to three sanitary pads a day. She only wears them when she is expecting problems such as exercising.

Preoperative interview summary

This lady said that she always had a problem but it was controllable, not embarrassing and not a problem. Since she had her daughter four years ago the problem has got worse. She says that everyone around her knows she has a problem and if she goes to the toilet they say *'oh, have you wet yourself again?'* She recounts a trip where she flooded and she could feel their embarrassment and her own embarrassment. She had a change of clothes and had to walk across a bar hoping no one would notice. She said *'I have to get something done. I could see the*

horror on their faces.' She would love to do exercise classes to loose weight but knows if she goes she will leak and would not know the people in the class so will not go.

She says her mum has a problem too and she won't go travelling and she does not want that to happen to her. '*She has her 4 walls and won't go anywhere.'* When she is with her family they say *'don't make mum laugh, don't make mum laugh, she will wee herself'.* She laughs along with them but in a social situation that they may worry that she leaks and they don't want her to laugh.

When her daughter was six months old she saw a signs and saw her GP who referred her straight away for physiotherapy. She came for a year and had improved but couldn't get any tighter and was referred (to urogynaecology). Then she had to measure her urine, how often she was weeing and when she was wet. She did that a couple of times and had tests including urodynamics. She saw consultant who offered duloxetine but she had severe depression so was recommended surgery.

After surgery she would love not to be able to wear pads. To laugh, go on a fair ride, an exercise class and just know she was not going to leak. '*If I wasn't leaking all over the place my family wouldn't be taking the Mickey out of me. That's it really. That is what I would like, for a life time really.'*

To manage the bladder she does not drink. She was told after doing fluid charts that she was drinking too much. She was drinking pints of water as she was always trying

to loose weight. She also will leave if she is laughing and avoids situation where she may leak, like exercise classes. She is always doing her pelvic floor exercises, always, because she did see an improvement with the leakage and on the computer.

She says that sex is a problem; she doesn't enjoy it because she is always thinking she is going to wee herself. It doesn't stop her having it but it is always at the back of her mind and she would be mortified if it happened while she was having sex. It has not actually happened. She usually feels she needs to use the loo and rushes off and then comes back, so it is always killing the moment.

Her three year old asks her *'mummy, why didn't you get to the toilet?' We potty trained her and we say '____, why didn't you get to the toilet?' When she says 'mummy why didn't you get to the toilet?' I feel so stupid then'.*

She also worries about smell. She changes her pad because she worries about smell or if she has a little leak. Her teenage daughters say *'you will smell like an old lady'*

Urodynamics

Preoperatively USI was demonstrated with no DO on filling and probably not provoked DO with coughing. Postoperatively she had a normal study.

Kings Health Questionnaire

Domain	Preop score	Postop score

General Health Perception	25	25
Incontinence Impact	100	33.33
Role Limitations	50	0
Physical Limitations	83.33	0
Social Limitations	66.67	0
Personal Relationships	66.67	0
Emotions	100	0
Sleep / Energy	8	0
Severity measures	86.67	40

Assessment of subjective success of surgery for stress incontinence (VAS)

She feels her operation has been fairly successful (scoring 8.8 where 0 is not successful and 10 is completely successful). She is satisfied with the outcome of her operation (scoring 9.95 where 0 is not satisfied at all and 10 is completely satisfied). At the time of the interview she felt happy (scoring 9 where 0 is very unhappy and 10 is very happy). She was reasonably relaxed at the time of the interview (scoring 2.1 where 0 is very relaxed and 10 is very tense). She still has some leakage (scoring 8 where 0 is leaks all the time and 10 is never leak).

Postoperative repertory grid

She can now laugh, which she could not do before the surgery. How she scored for how she is postoperatively, how she hoped to be and how she expected to be are all

very similar. The constructs she chose were about leakage, feeling relaxed or tense, happiness, pleased and wearing pads.

She likes dancing, socialising and keep fit and her constructs are mostly about her doing what she wants and choosing to do things herself. She does not like rude people, eating tripe or ironing and does not enjoy them and would not choose to do them herself.

Postoperative situations affected by incontinence

Before the operation laughing caused problems but now only a very slight problem on one occasion only. Keep fit was a problem before the operation and this is now a lot better. She could not go far from home before the operation and this is now a lot better. Nights out before the operation were a problem and this is now a lot better. Before the operation she was worried about having sex in case she leaked even though it never actually happened. Now there is no problem.

UI was less of a problem before the operation if she didn't go out. Now it is not a problem to laugh or exercise. She does not have to wear pads now. Nights out are not a problem now. She does not wear pads or extra protection now.

Postoperative interview summary

She said her operation hurt more than expected and she didn't think it would be as effective as it is. She feels more confident now '*cause I know in my head I'm not*

going to have an accident so I'm more confident. And it's just good to be able to do the things I've not been able to do for so long.'

It took her a while to recover. She thought she would be up and around but was still sore for a good week after. She still has a pain inside and it feels inside that something is not quite right in there.

In relation to her preoperative interview

1. How do you feel around your friends now?

The embarrassment. I like it now 'cause I'm not the butt of jokes anymore. So therefore I'm happier around them.

2. Have you had any episodes of flooding like in Blackpool?

No. That is the one that just horrified me. On Saturday I was with the friends who were in Blackpool and I had a laugh and I thought I had to go and they said 'no you've had an operation'. But it is still the talk. They bring it up time and time again. I think 'don't tell everyone' no, they don't tell everyone, but I can have a laugh about it now.

3. Have you been able to go to exercise classes?

Yes I have.

(How's that?)

I can go the whole hour without going to the loo and that's good, so hopefully I'm feeling a bit fitter now.

4. Have you been able to laugh with your family?

Yes

5. How do you find social situations with your family now?

I'm just more relaxed. More relaxed and I enjoy it more now. I'm not tense anymore.

6. Do you still wear pads?

No

7. Could you go on a fair ride?

I haven't been on one but I should imagine I'd be able to.

8. Have your family stopped taking the mikey out of you?

Em, my family have, as I say my friends, it's just good humoured between us.

9. Do you restrict your fluids?

Em, I can't say I've gone back to drinking the amounts I drank before my problems. I don't drink that much now, I don't do that purposely. I just don't.

10. Do you still have to leave situations where you laugh?

I did, the once on Saturday, em, that was okay, I was at home. I did make the toilet on time. I don't know if I wasn't at home what would have happened, but that is the only occasion since my operation.

11. Do you still do pelvic floor exercises?

Yes

12. What about sex?

I'm more relaxed now 'cause I don't think I'm going to have an accident.

13. Has your three year old made any more comments about mummy not making it to the toilet?

No, no. No, she hasn't. They have a short attention span haven't they? No she hasn't.

14. What about smell? Do you still worry about that?

No, not really. ‘Cause I’m not having the accidents I don’t worry about the smell.

15. Do your older daughters still mention how you might smell like an old lady?

Well they’ve said things like ‘we can’t call you the smelly cat woman anymore, can we?’ they’ve said that.

(That was what you’d mentioned. Is there anything else?)

I’ve been a bit worried about this pain in my side. Obviously I’ll get that checked out when I come for my appointment.

(What is the best thing about the operation?)

How relaxed I feel

(What is the worst thing about the operation?)

Just the feeling afterwards. The pain really.

(Are you pleased you had the operation or do you regret it?)

Pleased

(If a friend told you she was going to have this done what would you say to her? Is there anything you would warn her about?)

Just the recovery really. I was given the impression I’d be on my feet the following day, but I’d to take it easier. But I would recommend it.

(Is there anything the treatment hasn’t tackled or any ongoing problems?)

No

(Is there anything else you want to add at all?)

No

Case study 3

Preoperative repertory grid

How she hopes and expects to be is fairly similar. After surgery she expects to be able to laugh, run, not leak, not wear pads or think about the bladder all the time.

She like walking, gardening and knitting and these are relaxing, not boring, not strenuous and do not affect her vertigo. She does walking and gardening to keep fit also. In Contrast she does not like cricket, boats or spicy food. She finds them strenuous and not relaxing and boats affect her vertigo.

Preoperative situations affected by incontinence

UI causes her the most difficulties running, laughing and shouting. It is less of a problem sitting, walking and swimming. She wears all day pads and uses two per day to stop her getting wet.

Preoperative interview summary

She initially noticed a lump at the toilet and from watching programs knew it was probably a prolapse. Then she was wetting herself and sitting on a towel and wearing pads, which were not enough if she had an asthma attack. She also found she would need to go to the toilet and get there and there would be nothing, just trickles.

She started doing keep fit and she started using pads but it started to show through and would run down her legs so she stopped going. She stopped doing activities that would make her leak. She would go out for Christmas dos and things and by the time she got home she would be wet. She felt her peers did not say anything and feels that some of them probably have the same problem and no one talks about it.

She had a hysterectomy for a polyp and was a bit better. The surgeon said he had done a bladder repair and she hoped it would all be done in one but she still leaked.

She leaked today shouting across the playground. She said if she coughed now it would just run down her legs. She has been carrying things around for two years, so if it gets too bad she can always go and change. She has things in her bag now. If she has a bad asthma attack she keep wetting herself and gets embarrassed. She said '*I think you always think you are the only one, until you speak to someone else and you realise I'm not the only one.'*

She was hoping it would be better after the recent hysterectomy but it is probably as bad as when she had the bad prolapse. She was hoping with the hysterectomy it would all be over and done and finished.

She looked after her step mum who was incontinent and she thought '*please don't let me be incontinent'* and said *'I think if I don't have this TVT, I think it will get worse.'*

She said they were debating whether to do a bladder operation at the time but they decided that she did not need it. She said it is more that she couldn't empty because the prolapse was interrupting the flow.

She is always conscious of the bladder all the time. A couple of times she has forgotten spare pads and then needs one. She does a journey every week to see her

Dad and she hadn't taken a spare pad. She had to take the pad off, throw it in the bin and go without and hope she didn't cough. Otherwise she would wet the car seat, which has happened a few times.

Sometimes, when she has got really wet, her skirt gets wet as well. She wears light colours encase she sneezes or coughs. The other day she coughed and had to change. At least she was in the house. If she is bad she wears a dark skirt. But says '*I'm a light person, I like bright colours. I have wet another person's chair and I'm that embarrassed, you either tell them or you don't.'*

After surgery she is hoping she won't have to wear any pads and can do almost anything she wants. If she needs to run she can run and if she has an asthma attack she wants not to wet herself. *'If I have that, I have to worry about breathing too much to worry about all that. I haven't got to worry about wetting myself.'*

She is not worried about surgery but worries about the epidural she doesn't know why that worries her. Her friend had a TVT and she can't sit down to have a wee. She has to stoop, she can't sit, it just won't come out. She then asked if that was true. Voiding difficulties and positions were briefly discussed. Her friend says that otherwise it's given back her life and she is pleased she can now wear what she wants, trousers or a skirt and hasn't got to worry about leakage so she's really pleased.

She had tried ring pessaries for the prolapse but they didn't stay up. She said she didn't have any other treatment for the leakage.

She was hoping she wouldn't have to have this done. She thought the bladder repair was the TVT and found out two days before that it wasn't, they were just stitching the bladder up. She had urodynamics and said that when they ask you to cough she can control it. But when she is having an asthma attack she can't control it. She mentioned leaking at urodynamics and booking her operation then. She said they were going to try something else but they haven't. She was not sure what this was.

Her notes were checked and she was going to be discussed at the multidisciplinary team meeting and may need urodynamics. It said she may need a suprapubic catheter because there may be voiding difficulties. This was then explained this too her as was ISC.

She said it was obviously going to get worse. Sometimes she has to go home and is soaked. She feels she can't go on like that and can't enjoy her job. She says that the pads say they cut down the smell but she can still smell it. Her step mum had big pads and she doesn't want that. She thinks it is worth the risk. She hopes to be dry and won't wear pads anymore. That's her aim.

She would rather get done now and not when she is 80 years old wearing pads. She went through it for 14 months with her step mother. You'd leave her and she'd be

soaked. She'd put things on the chairs and it terrified her thinking she would be like that. If she had to pass a catheter she thinks she'd cope with that.

Urodynamics

Preoperatively USI was demonstrated and said to be moderate. There was some debate about whether there was provoked DO or not and felt there was not after the results were discussed. There was stable bladder filling. Postoperatively there was only a spot of USI with five big coughs and no DO.

Kings Health Questionnaire

Domain	Preop Score	Postop Score
General Health Perception	25	25
Incontinence Impact	100	33.33
Role Limitations	66.67	16.67
Physical Limitations	66.67	0
Social Limitations	33.33	0
Personal Relationships	50	0
Emotions	22.22	11.11
Sleep / Energy	66.67	66.67
Severity measures	86.67	26.67

Assessment of subjective success of surgery for stress incontinence (VAS)

She felt her operation had been somewhat successful (scoring 8.4 where 0 is not successful and 10 is completely successful). She is very satisfied with the outcome of

her operation scoring 9.75 (where 0 is not satisfied at all and 10 is completely satisfied). At the time of the interview she felt happy (scoring 9.6 where 0 is very unhappy and 10 is very happy). She also felt relaxed (scoring 2.4 where 0 is very relaxed and 10 is very tense). She now sometimes leaks (scoring 7.85 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grid

She is now able to shout which she could not do before because of the UI. She leaks more than she expected or hoped to but not as much as when she was at her worst. She is able to laugh and run as well as she hoped. She feels more confident than she expected to and as confident as she hoped. She now wants to go out which she didn't when her problems were at their worst.

She likes knitting, making cakes and gardening. Gardening gives her backache the others do not. None of them make her feel sick. They are all pleasurable and she enjoys their design. They vary in how much hard work is involved. She does not like going on boats, eating curries or going to the dentist. They make her feel sick and she sees them as a chore. They do not give her backache. She does not use UI in any of her constructs relating to activities.

Postoperative situations affected by incontinence

UI was a problem if she waited too long or was not able to find a toilet. Having to have spare underwear. It is less of a problem laughing, shouting, running and she

can go longer without have to go to the toilet. She does not wear pads or any extra protection.

Postoperative interview summary

Before she had the operation she was leaking everywhere and having to wear pads and keep clean underwear in her bag. After the operation she was still leaking for three weeks and had an infection that took five weeks to clear up. She still wore pads for around five weeks after the operation and then gradually started to not wear pads in the house but still wear them going out. She was on school holiday and didn't have to worry about being at work just in case she did leak. Now she doesn't wear any pads whatsoever but still carries pads and pants in her bag. She hasn't got confident enough to not have underwear in her bag. She finds she can go longer now in between going to the toilet, where before she was going every half hour, she can probably go four hours now. If she leaves it too long she will leak and also will leak if she doesn't get to the toilet quickly enough. She finds she doesn't need to go and then at the last second she does need to go.

She likes that she doesn't have to have smelly underwear anymore, when she has dribbled during the day. She is getting more confident about not leaking.

In relation to her preoperative interview.

1. Could you shout across the playground at work now?

Yes

2. What happens when you cough now?

So far I haven't had a leak and I have had an asthma attack. Before when I had an asthma attack in bed, I'd have to put a towel beneath me, but I didn't this time.

3. Do you still carry around things to change into?

I do carry underwear still. If I'm going on a long journey I put a pad on as well. I don't know why. I just do it. Probably lack of confidence I suppose.

4. Have you had an asthma attack since the operation? If so, was there any leakage?

Yes.

No

5. Have you had any embarrassment over the bladder since the operation?

No

6. Have you made the journey to see your dad since the operation? Did you take a spare pad? How was the bladder?

Yes. I didn't take the pad but I took some pants. I go every week to see my dad. Fine.

7. Do you still think about what colour your clothes are? Or need to wear dark colours?

Em no. Fine now. No.

8. Have you wet anyone else's furniture since the operation?

No

9. Have you been able to stop wearing pads?

Yes

10. Have you been able to run?

Em, it's a thing I can't do very often but I'd say yes I could. Asthmatics tend to stop you running, especially when you get to my age.

11. Did you have an epidural/spinal for the operation? How was that in the end?

I had a full one, they knocked me out. They were going to do an epidural but I can't lie flat, I get sick with vertigo. They said they couldn't do it unless I lay flat.

12. Are you able to sit down to have a wee?

Yes

13. Do you enjoy your job more now?

Yeh, I do. I don't have to worry in case I leak or shout or yell

14. Do you think there is a smell now since the operation?

No

15. Have you had to pass catheters yourself? If so, how has that been?

No

(What is the best thing about having the operation?)

Having a general anaesthetic. Knocks you out. It is just nice now it's settled down not having to wee all the time. Sometimes I surprise myself, I haven't gone for ages. But it is still the nighttime. I have to wake up at least three times per night to go to the toilet. I suppose the only thing that hasn't got any better is the nighttime. But I don't sleep very well. I think because you are semi conscious you are always aware of the need to go to the toilet.

(What is the worst thing about the operation?)

I don't think there is any. I can't say, I mean, I wasn't in any discomfort or any pain. The worst thing is the gooey stuff that came down for weeks. Even after the hysterectomy it happened. I always seem to have an infection. Years ago I always seemed to suffer with cystitis. I am trying to persuade my friend to have it done, but

she's a coward. To me hospitals are no problem. I could never have my ears pieced, don't ask me why, but I couldn't.

(Are you pleased you had the op?)

Interrupts yes

(Or do you regret it?)

Definitely pleased

(If a friend told you they were going to have this operation is there anything you would say to them?)

I'd tell her to go ahead and have it done. I've already told her. She has a prolapse and wets chairs, the same as me. I would recommend it to anybody if they're having bladder problems, have it done.

(Is there anything else?)

I can't think of anything else. That's covered most of it.

(That's fine)

She mentioned about the vagina, and I had noticed some cystocele during UDS. I referred her to physiotherapy for pelvic floor exercises and discussed taking care of the pelvic floor for the future and to seek a further referral should it become a problem

Case study 4

Preoperative repertory grid

Her hopes and expectations for after surgery are identical and very similar to how she was before she had any bladder problems. She wants to have no leaking, no

SUI, not wearing pads and to feel both normal and free. She chooses the middle of the scale (3 out of 7) when scoring her current leakage, SUI and feelings of normality. The extreme scores are for wearing pads all the time and not feeling free.
She likes gardening, walking and listening to music. She finds them relaxing, rewarding and she doesn't dread them. She does not like parties, going to the dentist and getting old. She finds these not relaxing, unrewarding and dreads them. She did not use UI in her construct formation.

Preoperative situations affected by incontinence

Her UI causes her the most difficulties lifting, coughing, sneezing, tripping and carrying heavy loads. It is less of a problem sitting and lying in bed. She uses one mini tena lady in the daytime and one normal tena lady at night. She wears them to keep from wetting her pants.

Preoperative interview summary

This woman was due to have a TVT but had also been put on duloxetine tablets and referred to physiotherapy but that appointment had not come through yet so she was not sure what she was meant to do. Over 10 years before she ended up with wet pants once or twice so started to wear a panty pad. That was the situation for a while and she worried and had bladder tests. She had physiotherapy for a while and bought cones. She couldn't fit them in to her schedule. She couldn't go out and had to stay upstairs encase they fell out. It took about 20 minutes. She didn't get up to the heaviest. She had a dog and I couldn't do anything because of her.

She had a New Years Eve at her brothers. She had some wine and was absolutely saturated. She doesn't think anyone noticed and had to go and get changed. More recently she had leakages and was worried because the leakages were coloured. Her doctor took a swab and checked the urine and told her there were bugs in it. Recently he put a stick thing in it and told her it was clear.

She bought tampax later because she didn't know where the leakage was coming from. She didn't get on with the tampax because as you get older you are dryer. When she was told she had thrush, she was worried because she had a hysterectomy but still has her cervix. She was worried there may be something wrong. She had no smears since 1974, she wasn't told and assumed it wasn't necessary.

Since she had the tablet it has not been so much. Her doctor put her on something beginning with 'd'. It wasn't duloxetine and she had a big leak watching TV. She thought the tablet was relaxing her bladder too much or something and stopped it. The colouring of the urine is not so much now.

She went to her GP because she kept wetting her pants. She was examined and told that over the 15 years or so her bladder had dropped. The doctor examined her a couple of months ago and told her it wasn't. She said *'There was me thinking it had dropped all this time.'* She mentioned her remaining ovary and how she was told it would wither away. She was trying to remember everything accurately.

She was given an appointment here for physiotherapy and had bladder tests. A nurse took her through pelvic floor exercises and after she had been coming two to three weeks she ended up with the carton canister of cones. This was over 10 years ago and since then she has gone on wearing pads and varying in how much she leaked. She just continued with it and had not had anything else to do with her bladder until this year when she became worried because she was losing more and because some of the pads were stained. She had an excessive loss after the first tablets. She saw her GP and then attended the hospital where she filled in a questionnaire. She mentioned the staining but wasn't asked about that.

She commented that she can remember what something begins with but not the word and said that short-term memory is a great frustration in older age.

After she had seen her doctor and he'd examined her, she decided she wasn't going to go on like this, using pads all the time. First she went to see a recommended gynaecologist, not a urogynaecologist. She referred her to the urogynaecologist but she got impatient and decided to see him privately. She said '*When I spoke to him he said the wait wasn't too long and as I haven't got thousands to spare'… (shrugs)*

She said '*He told me I could do nothing, but that 'you wouldn't be here if you wanted to do nothing', so try the tablets and at the same time the physiotherapy and if they don't work, the TVT.'*

At that stage she was prepared to go for the operation. She didn't want to wait and experiment and go longer. After that she talked to friends and her doctor. They thought she was wise to try tablets and physiotherapy but she hasn't heard anything from them yet. She wants to ask some questions at the end of the interview about that.

Her friends didn't want her to have an operation. All of them said that is her absolute last resort, so try other things first, which is what she has done. Whilst they haven't stopped it she thinks it has eased it a little.

She is expecting the TVT to work and stop her leaking so she doesn't have to wear pads anymore.

She has grown used to the bladder now and has fitted her life around it. She found one question difficult to answer. She is used to fitting around it and wearing pads all the time and can't really imagine without it. It is like having a period all the time. She carries pads around so she can dispose of one and have a fresh one. While she has got used to it, she would like it not to be there.

She felt she was not very clear and if her friend was with her she would remind her. She clearly remembers the times it has gone through her trousers. She had gone to the post box and tripped and had to go home. She was in pale trousers and had to go and change. She said that '*these occasions are not many over the years, considering how many years I've had it.'*

She asked if I knew of a particular Dr saying '*He'd been on the TV and said his TOT was much safer and better than TVT. He was quite derogatory about that and that only 10 surgeons could do it and he'd been to Rome to learn it. He wasn't very kind about the TVT operation. It was very scary. I've got a cutting here and that was his talking about TVT which he was saying was wonderful in April.'*

(I looked at the article. It was about TVT and was written by a Harley Street Dr who does TVT privately. We discussed the theoretical benefits of TOT and that NICE supported its use but it was not shown in practice to be safer at the moment. I said that TVT was done more often and currently was as good. TOT was not yet done as much and that perhaps in the future it may be shown to be better but that information is not there now. I also explained that Mr___ (urogynae) had done TOT and may be useful if women are fat or had a lot of surgery in the pelvis and if we had thought it would be better for her we would have suggested it. I did mention that the other option was the colposuspension, which had been around for longer but was a more major operation. She had not heard of that.)

(We also talked about specialist operating and how the gynaecologist she originally saw did not do TVTs but referred her to a urogynaecologist).

If it's too tight you may not be able to pass urine and if it's too loose it may not work

(I explained that it was not that exact but that in the operation you would be asked to cough so that the tape can be adjusted. I agreed that it was better done by someone who does a lot of these operations)

(I checked her notes and could see that she was offered duloxetine while waiting for surgery. Her GP had referred her to physio too but she had not heard anything. I phoned physio and an appointment had not yet been made for her but would be end of November at the earliest. I explained she could have her surgery as planned, postpone surgery until physios had assessed her and then postpone it further if they thought they could help her. Or just postpone surgery for at least 6 months to give tablets and physio the best chance of working. She was not sure)

I am still leaking but not as much, I'm just wondering if I tried tablets and physiotherapy, maybe that would make the difference; I don't have high expectations of it.

(I said she could either give the other things the best chance to work or decide she has had enough and go for the surgery)

I felt like that initially. My friends influenced me. My doctor thought that it was good that I was put on tablets and put on the waiting list for surgery to avoid delaying things. I have great faith in him he's very nice. I can see the sense in not having surgery. It's not the most major operation is it?

(It is not the most major but it's not minor either. All surgery has risks)

I have taken risks with the hysterectomy and cataract operation there is a risk to everything.

(I agreed with her that there is risk in everything and talked about crossing the road. But also that you can cross the road at lights which may make it safer but you can still get knocked down)

I'm torn between getting it over and done with or ought to try the other options to have the patience to wait

(She was not sure how to proceed and I suggested that she went to her preoperative clerking and keep her surgery date and if she wanted to change anything to let me know and I would try to sort it out.)

She telephoned the ward later the same day and left a message for me to say that she was going to keep her surgery date but was going to get out her old leaflets and try to do pelvic floor exercises on her own. She also said that she had enjoyed the interview.

Urodynamics

Preoperatively USI was demonstrated. Postoperatively a very minor amount of USI was demonstrated.

Kings Health questionnaire

Domain	Preop Score	Postop Score
General Health Perception	25	50
Incontinence Impact	66.67	66.67
Role Limitations	66.67	33.33
Physical Limitations	66.67	83.33
Social Limitations	11.11	44.44
Personal Relationships	33.33	0
Emotions	33.33	55.56
Sleep / Energy	50	50
Severity measures	66.67	53.33

Assessment of subjective success of surgery for stress incontinence (VAS)

She did not feel her operation had been successful (scoring 3.6 where 0 is not successful and 10 is completely successful). She is not particularly satisfied with the outcome of her operation (scoring 3.7 where 0 is not satisfied at all and 10 is completely satisfied). She feels unhappy at the moment (scoring 1.65 where 0 is very unhappy and 10 is very happy). She is neither relaxed not tense (scoring 5.1 where 0 is very relaxed and 10 is very tense). She still has leakage (scoring 3 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grid

Since the TVT she is close to how she expected to be with regards to leakage with coughing. She is more similar to when her problems were at their worst than how she expected to be in regards to leakage, confidence and depression. She is about midway in relation to ability to do physical activity and in social activity being affected by lack of confidence.

She likes gardening, reading and listening to music they are quiet activities that make her feel happy and satisfied. She hates inactivity, cruelty and man's blindness to what we are going to the planet. These make her unhappy, frustrated and dissatisfied.

Postoperative situations affected by incontinence

The most difficulties are encountered in bed at night, getting to the loo in time, sneezing, sometimes walking, getting up after sitting some time. Things are not quite so bad with coughing now. She is wearing two tena lady mini pads per day to stop wet pants.

Postoperative interview summary

She said she is wondering whether she has messed it up. She said for the first few weeks she followed the instructions on the sheet to be very careful and her friends helped her as she lives alone. After that time she was aware she had lifted weights and had discomfort and started to have a coloured discharge having had a clear one for a while. She thinks the lifting started this saying '*That depressed me 'cause I thought I'd done it myself. My friends said '___ (name) you should have phoned us,*

called us, not done it'. But you live on your own and get on with things. That is the picture I have, that I might be my own worst enemy.'

She also said *'I've got just a ray of hope in the sense that in the form it says 'if after 30 weeks you are not recovered they would offer a colposuspension'. The fact that that says 30 weeks makes me think there is hope that there is time for this to go right'*

She has been feeling a loss, a leakage during the day, when she has been walking or sneezed, into a pad. The worst thing is in bed at night the bladder does not seem to wake her up. She wakes up and finds she needs to go to the loo and gets up and her panties and pad are soaked. This has happened several times. She used to have an urge to go and got up to the toilet. Now she doesn't have the urge but when she gets up, there is the leakage. She only has to get to the door. That is the worst thing, it was not immediate more in the last few weeks.

She was worried she had lost the sensation. Today she had a drink to help the test and she is aware she needs to go to the loo, so she knows she hasn't lost the sensation and says '*So I don't know why it doesn't wake me up in the night. Oh dear, life's complicated isn't it.'* She is wondering whether time will make a difference.

Based on the preoperative interview

1. Do you still have leakages?

Laughs yes

2. Is the urine coloured anymore?

No, not really. No not really.

3. Are you still wearing pads? All the time?

Yes. Yes

4. Do you still feel worried about the bladder?

Yes

5. Are you still fitting your life around your bladder?

No. Only at night *laughs*

6. Do you still carry pads around with you?

Yes. There is always that anxiety that the pad won't cope. It doesn't cope at night. So far it has coped during the day but, and then there are stretches when I lose nothing.

7. Have you had to go home and change because of any leakages since the operation?

No, not since the operation.

8. How do you feel about the decision for surgery now?

Oh, I'm glad I tried it. I just say I'm worried I may have scuppered it. I didn't enjoy the epidural, I hated that.

(Why?)

Well, I found it painful when it was being administered; he had a couple of goes. I yelled and said it went down my legs and he said 'good that's what I wanted'. I hated coming round from it. From under my bust to my toes I felt I wanted to move but I couldn't and I felt panicky. I could see why they did it, needed to be awake to help, so I understand why it was, but I didn't like it.

(Are you pleased you had the operation or do you regret it?)

I wouldn't alter my decision. So I don't regret it.

(What is the best thing about having the operation?)

I tried to improve my situation. Em, and I think, apart from this problem at night, I think I am a bit better during the day than I was.

(What is the worst thing about the operation?)

Well, just that thought in the back of my mind. Whether I can no longer tell my bladder's full. I can now, so that can't be the case. I wonder why it is I don't wake up at night. I used to wake up several times at night. I don't know, I could even go right through. It goes to sleep at night, I don't know why.

(If a friend told you she was going to have this operation is there anything you would say to her?)

Em, only that I hoped she'd be in the 80% that are successful. I certainly wouldn't put her off having it done. I'd certainly warn her about the epidural if she'd never had one.

(Is there anything else that springs to mind?)

Not at the moment

Case study 5

Preoperative repertory grids

Her hopes and her expectations for after surgery were identical and were to be physically active, not wearing protection or leaking, not feeling left out, feeling younger and not embarrassed. She would like to play badminton. She enjoys spending time with her children, running a brownies pack and sitting in the sun reading a book. These give her pleasure are related to family, not intimidating, able to learn something from it. Other constructs varied in their strength were listening and

responsibility. She does not like driving on the motorway, untidiness and bad language and swearing. The constructs were not consistent around these.
UI was not mentioned in these constructs.

Preoperative situations affected by incontinence

UI causes her most difficulty, as she is unable to rush anywhere, especially for her train. If she is going anywhere with people she tends to double up her protection in case she leaks or cannot find a toilet. She turns down invitations that involve activity. She always wears dark clothes. Although she can last three to four hours for the toilet she repeatedly goes to the toilet before leaving the house. Her incontinence is less of a problem to her when she is in comfortable surroundings i.e. at home and relaxed, when she is sedentary i.e. at work, watching TV, when she is active but not rushing, when she has more time to go more slowly if necessary and when she is with people she knows, with whom she can laugh it off. She always wears panty liners plus a thick sanitary towel if she knows she is likely to be in a situation that may cause her to leak. She uses two pads a day to capture any leakage and to give her confidence and to stop her getting into an embarrassing situation.

Preoperative interview summary

This lady was seen privately. She is due to have a TVT, vaginal hysterectomy and repair. She doesn't remember the start of her problems but thinks it has probably been a long time. She believes it began after her first child, which was a difficult birth. She says that the midwives were determined she was going to have this baby naturally and she was pushing down for two hours and she believes it all started

then. She doesn't really remember leaking she had another child five years later and that birth was much easier.

She can remember being on a family walking holiday about 10 years ago and she wet herself giggling. She saw her GP who said there is a difference between a fit of giggles and losing control of your bladder. That is when she started wearing protection just in case.

When her children were growing up she was wetting and that was fine. When they were learning to cycle it was fine at first but as they got proficient she couldn't run after them and would wet herself. That was 12 years ago. Her mother said to go to the doctor for a check up in case something might be wrong inside. She did go and was sent to the physiotherapy clinic where she had quite an intensive time, 19 sessions. She went to the incontinence clinic and had pelvic stimulation. She can remember the physio saying it was good one week but was pathetic the next week. She thinks when they reported to the doctor they said that there was a slight improvement, which she thinks was disappointing to them. She bought herself a set of cones and did exercises and did not give up.

She works in town and gets the train and it is downhill. There is no way she can get the train unless she has been to the toilet before she leaves the office. There is no way she'd get down that hill. She read in magazines that there is a big operation and I couldn't consider it with young children. She saw an article and rang a help line and they said about the TVT but it was new and maybe not yet. She said you see it in all

the magazines now; it's everywhere, pad adverts. She thought if it could be solved with a tape. She will be 50 this year and thought she can sort it out before then.

Initially she got confused why she had gone to the GP and then remembered. She did a walk for breast cancer and was training with a friend and completely wet herself. Usually she dribbled and it is contained but it wasn't. Her GP is really nice and she can talk to her so she told her about the bladder and she had an internal. She had a prolapse and wondered if the two were connected. She was referred to the urogynaecologist who did an examination and took a history and said she had a severe prolapse. He wanted to do urodynamics and was looking to possibly do a vaginal hysterectomy, TVT and a repair of the vaginal wall.

She went for urodynamics and could not fill her bladder as she was going from work and thought there is no way she will get there with a full bladder. They hooked her up on the table and she felt the pressure. She describes how they pump this bag into you. They were going to tip the bed. She said *'I am going to leak'. 'No, no you wont' they said 'you're doing well'. I said 'I will and I wet everywhere it was so awful'.* Mr_____ (urogynae) was a little surprised, as she hasn't got any urge and took it to the team. He wrote to her that the consensus was to carry on even though there was an increased risk of urgency and if it happened it could be treated with tablets.

'I took this back to my lovely doctor. I was anxious of that surgery. I thought I was coming 'can I have a tape please'. I wasn't expecting all this I felt very unsure. She advised me to go for it. My quality of life was restricted.'

She feels it is impacting on her life but '*I'm sure I'm not as bad as some women who are housebound and packed up to their ears.'*

She saw Mr_____ (urogynae) again with a very long list of questions. He said it was entirely up to her and he could just do a TVT. His advice was just to have everything done. He was surprised she wasn't having symptoms. He made it quite clear that it was her choice. His recommendation was to have everything done. That final consultation/interview put her mind at rest. She feels she is just a layman and likes to know that it is their opinion that it is the correct thing to do.

Straight after surgery she assumes it is going to be pretty grotty. She thinks the hardest thing will be sitting still and getting better but she realises that she has to do that and is a bit anxious. She says she has managed it for years and now she is going to interfere with her body. She is concerned that she isn't going to do well. She supposes it is in the back of everyone's mind. She has done all the preparation, the big shop and will do what she is told. She imagines she is going to have a couple of months off. She is not sure how she will be once convalescence is over she is hoping she will be able to do more adventurous things.

She describes her restricted fluid intake and feels it is less than recommended. After surgery she would like to drink copiously and hold it. She manages her time so she doesn't have to run for the train. She can wait to go to the toilet but before she leaves

the house she goes up to three times, she might just have a dribble, but she goes just in case, and she feels it is totally unnecessary.

She always wears a panty liner and carries spare ones. If she knows she'll be under pressure or out all day somewhere strange she wears a sanitary towel. If she has forgotten spare pads she feels anxious and goes into a panic attack.

She hasn't worn a skirt for years and would like to be able to do that. She feels more protected in trousers and always wear dark colours. She would like to have worn khaki shorts for a walking marathon as it was warm, but stuck to dark trousers.

It is the fear of things sometimes rather than them actually happening.

Over the years she has turned down tennis group and aerobics sessions with friends. She read recently that one in four women at a tennis club are wearing a pad and leaking. She thinks we should speak about it more as the people she has spoken to have said 'oh, I leak and do this and thought it was okay'

She doesn't need to rush to the toilet but is conscious of where they are. She has tried pelvic floor exercises and cones but lost heart. She also bought a toner from a magazine earlier this year.

Her consultant said whatever exercises you do, unless you are lying down so the prolapse is out of the way, won't work. That made her feel better. Once the damage

is done it is done. You are standing at the train station doing these and it does not make it any better.

She asked Mr____ (urogynae) what is the situation for her daughter. She thinks she could have been slightly better managed herself. She says '*I think we could look after these bits we don't see, we aren't really aware of it till childbirth. It's almost too late and then we get the information.'*

She says if you go to someone's house you are aware of their furniture. If they have a beautiful pale suite she'd prefer to sit on a dining chair. If something happened she would be mortified if she leaked on somebody's beautiful suite. If she were with someone having a good time and giggling, playing a board game or whatever, she would be conscious not to relax completely.

She thinks education is important for young women. She says she has no idea about these things but Pilates seems to focus on the centre of your body and she is going to try to find a class like that. She feels we focus on the outside but the inside is just as important.

She said '*I haven't got a partner. I'm divorced. That lets me off the hook. If I had a partner I'd probably be sitting here squirming'.* She says she probably went to the loo before intercourse and made sure she was comfortable.

Then she asked me not to write something down.

(She then talked for a few minutes and I did not record anything. She then started talking about the surgery and she allowed me to start writing again.)

She says it became much bigger than she anticipated. She has got no one and has a 12 year old daughter and is the bread owner. She is concerned is it the right time? She is concerned if she leaves it until older, she may not be so well. Her mum can take the reigns for a while. If she had the two operations separately she would have two recovery periods.

She feels like a bit of a cheat, as these are just physical things not ailments. She feels someone else may needs treatment more and that makes her feel guilty *(starts to cry. Given tissues).* She feels she is not struggling the way some women must be and thinks she is a bit of a control freak. She is responsible for the bills and the home and it's just letting it all go.

She says it is quite a big thing isn't it? She helps elderly ladies out and struggles to allow others to help her. But she feels it will be nice for other people to help her for a change.

Urodynamics

Preoperatively she had severe USI and DO at capacity. She leaked on standing and was either SUI or provoked DO. Discussed at multidisciplinary meeting as no

symptoms of OAB and decided to proceed with surgery but advise risk of OAB. Postoperatively her urodynamic study was normal.

Kings Health Questionnaire

Domain	Preop Score	Postop Score
General Health Perception	100	0
Incontinence Impact	66.67	33.33
Role Limitations	50	0
Physical Limitations	83.33	33.33
Social Limitations	44.44	11.1
Personal Relationships	N/A	N/A
Emotions	44.44	22.22
Sleep / Energy	16.67	16.67
Severity measures	40	33.33

Postoperative assessment of subjective success of surgery for stress incontinence

She felt her surgery has been successful (scoring 8.55 where 0 is not successful and 10 is completely successful). She is satisfied with the outcome of her operation (scoring 9 where 0 is not satisfied at all and 10 is completely satisfied). She feels happy at the moment (scoring 9.3 where 0 is very unhappy and 10 is very happy). She is feeling relaxed at the moment (scoring 2.75 where 0 is very relaxed and 10 is very tense). She does not leak (scoring 9.95 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grids

She is very close to how she hoped to be and even better than how she expected in relation to her constructs which were feeling free, not embarrassed, happy, active and able to join in. she is able to leave the house without going to the toilet now. She enjoys driving with her son, walking and reading. These are pleasurable, uplifting and she has some control. She does not like mess, arguing and dark rainy days. She finds these displeasurable and unplanned. Her other constructs score inconsistently but still give insight to how she perceives and values things and these are alone/in company, unplanned/planned and friendly/unfriendly.

Postoperative situations affected by UI

Her incontinence causes/caused problems when desperate need to go to the toilet in public (postop), walking and leaking urine (before op), running for the train and leaking urine (before op), having to pack absorbent pads on every outing (before op), feeling unable to join in activities with friends/ declining invitations (before op).

Her incontinence is less of a problem to her as she is able to walk and not leak urine (postop). Pads are worn but are no longer wet (postop) and there is no need to pack extra protection (postop). All of this is less of a problem if the people she is with are friends and aware of her bladder (postop). She is most comfortable at her home or at the homes of friends (pre and postop). She still wears extra protection in the form of one panty liner per day. She wears them for reassurance and out of habit.

Postoperative interview summary

She had a TVT, vaginal hysterectomy and repair and she understood that the surgeon had been satisfied with everything, which she found reassuring. She was surprised not to have any pain so stopped painkillers after three days. She describes needing re catheterised twice because she wasn't weeing enough. She got a UTI because the catheter was in and out so many times, and that delayed her going home. She thinks everything went wonderfully well and the care from everybody was exceptional. She has antibiotics for infection and an injection for the sickness which improved quite rapidly and she was able to go home the next day with a catheter and leg bag. She thinks that alarmed everybody else more than her and she was able to manage bathing and showering and changing it quite easily. She was able to rest as her mother was running the house and family. She thinks that helped her to get better quicker.

She went back into hospital for a day, for a trial without catheter, and was still unable to pass significant volumes. She was sent home without any catheter and asked to report to the hospital in two days time. She was still retaining large volumes and was taught ISC by one of the nurses. She found the nurse amazingly understanding about this, as it was all a bit peculiar and a bit strange to her. She was very calm and gave her plenty of time to get used to the idea. I was sent home and asked to catheterise myself morning, noon and night, which I quickly got in the pattern of doing it, in the privacy of my own bathroom, with all the bits around me.

She describes running out of catheters making her very anxious, as she was concerned that the pressure building up in her bladder would undo some of the good of the operation. She rang the hospital and the staff was very reassuring. She also made numerous calls to the catheter company and received the catheters the following day.

She settled into a routine of self-catheterisation and rang the hospital on a weekly basis with her volumes. They advised her to reduce the catheterisation to twice daily for a week, then to once at nighttime, and then the following week not at all. They then told her just to catheterise herself once, the night before her check up.

She is glad she had the operation done and found it quite difficult to decide whether to have it done or not. She is glad it is over and done with.

Today she feels fantastic compared to how she felt when she came out of hospital because she had a catheter and was looking at having to catheterise herself and wasn't sure where she was heading. With the kindness everyone has shown her and showing her exactly what to do she has been able to do what she was asked and is now catheter free. She feels thankful; that it has been a relatively short time as she thought she may have to do it going back to work and using public toilets.

The only thing that has been of slight concern is a desperate feeling of needing to go to the toilet every now and again. She hopes that will settle and has been advised today that six weeks is still early days and it will be at least six months before it is a

real concern. She feels very lucky that surgery went well, that her hospital care was so good, that she didn't experience any pain at all. She thinks it is fantastic and that her bladder problems are settling and she is looking forward to being able to run for her train without leaking, play badminton without leaking and enjoy the improvement that the operation has hopefully made.

Relating to the preoperative interview:

1. Have you been able to laugh without leaking since the operation?

Yes

2. What about getting the train from work?

I've not gone back to work so that is untried

(Would you like to guess?)

I guess I'll be good and able to do it

3. Do you go to the toilet before leaving the office?

(Not back at work)

4. How is the downhill walk now to the train station?

(Not back at work)

5. How did you feel straight after surgery? (Was expecting to be 'pretty grotty')

Nauseous, I was sick. I can't believe no pain. I suppose that is what modern medicine is about but you expect a twinge or something wouldn't you?

6. How was the recovery time? (Was worried about doing nothing over the recovery period)

It has been difficult not to do things but my mum has been with us and taken the household reigns and I did everything I possibly could do beforehand and it's all

learning curves, having to ask for help and let things go. First of all I wanted to be a nurse to help people, I help a lot of older people and it makes you empathic being on the receiving end of things. Sometimes you want things done your way but you can't 'cause you're not doing it. Having to use a catheter and sit with a leg bag beside someone, it makes you think how anyone could be struggling in ways you can't see. It has opened up my life experiences a bit; I've never had anything to do with hospitals myself particularly.

7. Have you been able to do more adventurous things?

Not yet, 'cause I'm not allowed, am I?

8. Do you still restrict your fluid intake?

Not at all, no, I'm drinking lots now

9. Have you been able to drink copiously? And hold it?

Yes, only just

10. Do you/ could you run to the train?

(Not back at work) (Do you think you'd run to the train?)

I'd have a go

11. Do you still go to the toilet before you leave the house? How many times? (2-3 before) do you go to the toilet 'just in case?'

No. I'm trying not to. I wouldn't. I'm trying not to

12. Do you still wear a pad?

Yes, just a panty liner. I don't know why. If I couldn't hold it that wouldn't stop it. It's probably just habit.

(Would you prefer not to)

It's just me. I think I'd have to get rid of it gradually, at home first, just to prove that it's okay and then go for a walk or something

13. Do you still carry spare pads around?

No

14. How is it if you are under pressure?

I haven't felt under pressure whilst off work

16. How is it if you go out for the whole day? Do you still wear a sanitary towel as well as a panty liner if you are going out for the whole day?

I haven't been out for a whole day. I think at the moment I probably would. You know I said I needed to go. I think about the whole lot going.

17. How would you feel now if you did not take spare pads out with you?

N/A (does not take spare pads)

18. Have you been able to wear a skirt?

I haven't worn a skirt, so busy catheterising, just being at home

19. Do you still stick to dark colours?

Yes

20. Do you still feel afraid of something happening?

It's different now. It's not the leaking. It's not getting to the toilet in time. Afraid is too big a word. I'm not thinking about it all the time, just when the urge comes on me. Concern perhaps rather than fear.

21. Have you been able to go to anything with friends- like tennis or aerobics?

I haven't yet

(Do you think you'll try?)

I think so. I'd try exercise

22. Have you been able to talk to people about the bladder problems?

Oh yes, non-stop. I've come out of my closet. I'm a real hospital, I talk about my surgery. I think it is good, people say this and that to you, it liberates them. Before it is not quite right. With the catheter it seems okay to talk about it and acceptable. It's strange isn't it?

23. Are you still conscious of where the toilets are?

Em, yes, I suppose so

24. Are you still aware of other people's furniture? Would you be happy sitting on a beautiful pale suite? Or would you still choose a dining chair?

I think at the moment I'd probably go for the dining chair

25. Are you still worried about relaxing and having a laugh in case you could leak?

No

26. Did you find a Pilate's class or something like that?

No, but I think that would be good and I intend to explore that

27. How would you feel if you met a prospective partner?

Better. Isn't that good!

28. Do you feel that this was the right time for surgery for you?

Definitely, definitely

29. You felt guilty about the operation beforehand, as there may be people worse than you. How do you feel about that now?

I think I've been very lucky to have had it. I think perhaps there are people worse then me but I stepped forward. It was my turn.

30. How did you find letting other people help you during your recovery period?

Difficult. But very appreciative

(Are you pleased you had the operation or do you regret it?)

No regrets

(What was the best thing about having the operation?)

The fact that it solved the problem. And that they won't affect my life anymore

(What was the worst thing about having the operation?)

Walking to theatre and thinking that might be it *(make choking gesture)*. Are you doing the right thing? Is it going to make it worse?

(If you had a friend who was going to have this operation is there anything you would say, warn or advise her about?)

I'd just advise them to get all the information they could and discuss it fully with the consultant. I couldn't say if it would be right or wrong for them 'cause they're all individual. I could only tell them of my experience advising that theirs could be completely different. I feel very lucky as I could be sitting here with a catheter. I would feel different. You can only speak of where you've come from can't you

Case study 6

Preoperative repertory grid

She would like to be able to run and jog. Her expectations and hopes for after surgery are similar and are not having bladder problems, being able to control the water, able to run, feeling cured, normal and excellent.

She enjoys exercise, taking the dog for a walk and family life. The likes doing these, some of these she does for herself, they no not slow her down and make her feel

great. She does not like getting up late, being taken advantage of and a certain person. She hates these and they are to do with someone else, slow her down and she avoids them. She did not use UI to form her constructs.

Situations affected by incontinence

UI causes her problems during exercise, at functions, if there is no instant use of a toilet, in company, shopping. It is less of a problem at home and at relatives. She uses about three tena ultra mini pads per day and wears them all the time for dripping and leaking.

Preoperative interview summary

This woman wanted her husband present. This woman has had bladder problems from her childhood. She also remembers her mother suffering with a weak bladder and says it could be in the genes. Her own daughter thinks she will be like her when she is older and is starting to have problems, she is 40.

The worst time was when she was at a wedding. It just started running and she couldn't control it. Everybody knew about it and she was ostracised because of it. When she is walking the dog sometimes she doesn't even know she is leaking. It usually takes her 30 to 40 minutes to walk the dog and when she gets home she suddenly has to go and doesn't reach the toilet upstairs. Sometimes the pad is wet and she didn't even know she was leaking.

She doesn't know what else to do and there doesn't seem to be control over it. She got to the stage where she wasn't drinking and found out it wasn't doing her any good. Now she is drinking a lot more and it's no worse and she doesn't know how to explain that. She describes urgency. When she is out socially she usually asks her husband to remind her to go to the loo because she doesn't realise when she needs to go. She always keeps a spare pad on her.

She did not seek help until recent years. She didn't say anything to the GP until recent years when it got so bad she wasn't in control. She coped with it as something everybody got when they got older, the norm.
Her GP put her on a course of tablets to start with. Nothing she has ever done has been of help including a survey for duloxetine. I had an operation with the other guy. Not Mr___ (urogynae). She had an operation and was told it would help but she doesn't think it did a thing. '*If you knew who I was talking about you would understand. He was a very definite man. Mr ____ (urogynae)'s boss or used to be. He said it has got to have helped. 80% better. Would you give it a 70%? I think we agreed on 20%, I don't know why. He was trying to put words in my mouth, but I don't think it helped at all.'*

She had physiotherapy for 12 months and Pilates, which didn't help. She said a lot of people said to stop and start the flow. There is no way she could do that, which is why she started Pilates. She feels it has strengthened her inside but it hasn't benefited the water.

'*I used to put my hand on my stomach and there was no resistance now it is solid. I feel like there is a tap I need to turn off and I just cannot turn it off. If I turn the tap on it flows. It flows, that is the word for it.'*

She has always been fit and healthy and lived well with diet and health. She doesn't think it's anything she has eaten or anything. She has always drunk water, except for a couple of months, when she cut it all down.

She is having an operation because she thinks they tried everything else, everything they possibly could and this is the final stage. She was told it might not be 100 percent and she has read up what the surgeon said on the internet on his website. She thinks she has more confidence in him and his work than he has. She is expecting with his operation and her doing everything that she is told she wants to get back fit as quick as she can afterwards to make the operation good and stop this leaking and turn the tap off. Because of Pilates her muscles are very very firm everywhere and she feels that's got to help. She is trying to get herself as fit as possible before the operation so she recovers afterwards.

She feels her problem is being very impatient wanting to be able to do everything now.

She thinks Mr___ (urogynae) is absolutely brilliant. '*I like his attitude, very professional. I trust him implicitly. I know if he can do it for me he will and I'll do everything in my power to make this operation a success in the end.'*

She had a hysterectomy and was in for a week and believes it's a similar operation. She had the operation at a private hospital. She had one week at hospital and one week at home and went back to work. She did take it easy and do what she was told to do. '*In a hysterectomy, people have 3 months off work 'cause they're being paid. To me it's a waste of time. I don't do anything I shouldn't do. The sooner it's over and I'm mobile again, the better for me. I'm positive you know. I don't believe in anything that's negative.'*

She wants to be fit and healthy for the rest of her life. This is the only health problem she has had that's persisting and a nuisance. '*I don't like anything interfering with our world. We do things good for us, for the family. This isn't good it stops me doing things.'*

Urodynamics

Severe USI on video urodynamics preoperatively (as she previously had TVT). Void showed a strain pattern so she had duloxetine first. Postoperatively there was no USI. She did have provoked DO after five coughs standing with a big leak and was started on anticholinergics.

Domain	Preop Score	Postop Score
General Health Perception	0	25
Incontinence Impact	66.67	66.67
Role Limitations	83.33	33.33

Physical Limitations	50	33.33
Social Limitations	55.56	11.11
Personal Relationships	0	0
Emotions	11.11	22.22
Sleep / Energy	33.33	33.33
Severity measures	66.67	60

Assessment of subjective success of surgery for stress incontinence

She felt there had been some success from her operation (scoring 7.1 where 0 is not successful and 10 is completely successful). She is neither satisfied not dissatisfied with her operation (scoring 5.6 where 0 is not satisfied at all and 10 is completely satisfied). At the moment she feels neither happy not unhappy (scoring 5.4 where 0 is very unhappy and 10 is very happy). She has some leakage (scoring 7.4 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grid

She has many more bad days than she expected. She has a little more leaking than she expected but not as much as when she was at her worst. She is improved and happier. She enjoys sewing, nights out and her grandchildren. She does not like tea, leaking and being taken advantage of. Her bipolar constructs around the activities involve enjoyment, based in or out of the house, making her sick, her will or her body taking over, control, feeling content.

Postoperative situations affected by incontinence

Her incontinence causes her most difficulties walking, when other people are around, when she needs to dash to the loo, on a night out, when she can't change clothing. UI is less of a problem to her at home and in bed. She wears at least two Tena mini extra a day because if the leakage wants to flow she has very little control – also 'just in case'.

Postoperative interview summary

Her operation surgically was very good and the scar healed well. She had two bladder infections. In six weeks about eight times she has had to change her clothing because she has flooded when out walking and in the house. Her Dr sent some urine to be checked by the hospital for infection and gave her some tablets for five days. She is not sure what they were. The scar has healed on the outside but on the inside it feels hard and numb.

She built up walking to two miles a day. She had done three quarters of the walk, making sure she'd emptied her bladder previously and it just ran. She said there was a teacupful and she couldn't control it at all. It seemed out of the blue, she wasn't expecting it at all.

When she goes to the toilet it stops and then starts again. Then within 10 minutes she needs to go to the toilet again, a morning ritual. It happened a few times before the operation. She was hoping it would clear up. She thought it was maybe the weather.

Based on the preoperative interview.

1. How has walking the dog been?

When I was talking about walking it was walking the dog. I have always got the dog with me if I'm leaking or not. She's not always willing but I drag her the first few steps. I do two miles in 30 minutes I don't know if that is of interest to you?

2. What about when you get home? (Used to rush up the stairs and not make it)

I usually have to do that. Still do that.

3. You used to find your pad was wet and you did not know you were leaking- does that still happen?

No it doesn't, now you said that. It doesn't.

4. Do you feel that you have more control over the bladder now?

Em, huh, maybe a little but I'm getting these big leaks

5. What about the amount you are drinking at the moment?

Laughs you shouldn't ask me that today. I'm not drinking very much but that's because of the sickness and diarrhoea I had yesterday.

(Apart from today and yesterday?)

Apart from today, I think, I drank normally. I do drink a lot of water. I probably do two litres a day. I used to live on coffee but two's the most they say and then it's decaf.

6. Do you still have to get to the loo quickly sometimes?

Em, yeh.

7. Do you still get your husband to remind you to go to the loo when you are out socially?

Em, yes. That's not so bad though. We had a big dinner dance, I just didn't drink but I was going to the loo every hour, just in case, as I was in an evening dress. I didn't even drink, just water.

8. Do you always realise when you need to go to the loo now?

Yes, I think I do.

9. Do you still always keep a spare pad on you?

Oh, yeh

10. You said before that your stomach felt solid. Is that still the case?

Em, yeh

11. You said before that you feel it is like there is a tap flowing that you cannot turn off. Do you still feel like that?

That's when the leaking is, as though it is not under my will. (So that is just the same?) Um nodding

12. Has the operation stopped the leaking? (And turned that tap off)

No

13. How has your recovery afterwards been?

The recovery from the operation was great. I was out on Thursday and had my stitches out on Saturday. In on Sunday, operation on Monday. I think it is because I am physically fit and I'm not a whinger. It has to be done so it will be done.

14. When did you go back to work?

I don't work

15. Does the bladder interfere less with your world and family life?

Well, it still is. I'm still anxious, still expecting these flows to come. They are always when I'm mobile. I think that's it.

16. Does the bladder still stop you doing things?

Em. Yeh, it stops me being in complete control of myself. I haven't tried jogging.

(Is there any reason?) Well, this, sort of eh, I can feel the inside objecting to it so it's not ready for it.

(Do you feel pleased or regret that you had the operation?)

Oh no, I'm pleased I had it done

(What is the best thing about the operation?)

I think if you give me more time it will get better. It will improve over the weeks and months. I don't think my inside has healed up properly yet. It is still painful, that is only when I touch it.

(You think the best aspect is still to come?)

I think so. I don't know if it is the infections that have stopped me 'cause I was doing well. I think I was doing well.

(What was the worst thing?)

Oh, probably that I can't exercise yet. I'm probably getting towards it. I'm building up walking but I'd like to get back to my Pilates and proper stuff. I thought I'd get back yesterday but because of that sickness and diarrhoea. My stomach's just raw.

(If a friend was going to have this operation is there anything you would say?)

Oh, I'd definitely tell them to go ahead and have it done. Most definitely. When I was in there I saw so many people moaning. The nurse took a woman to me when I was in to have my stitches out. I was already out. It was good. Everything went well.

Case study 7

Preoperative repertory grid

She would like to be able to run and she cannot do this at the moment. Her hopes and expectations for after surgery are very similar and are to have no problems, not to be embarrassed socially, able to run, not feeling cautious, not wetting herself and not wearing pads. She hopes to be exactly how she was before the bladder problems started in relation to these constructs.

She enjoys walking, cycling and reading and she looks at these in terms of being outside in the fresh air (or not), acceptable, relaxing, not frustrating and enjoyable. She does not like running, shopping or untidiness and finds these unacceptable, mostly indoors, tense, frustrating and not enjoyable.

Situations affected by incontinence

Her UI causes the most difficulties when running, drinking fluids, when not at home, changing position, when in a hurry, on holidays and shopping. It is less of a problem at home, at work, knowing where the toilets are, when she has extra pads to change and when she is going out for short periods. She wears small pads or panty liners, using between three and 15 per day. She wears them to prevent her underwear and trousers getting wet.

Preoperative interview summary

This lady was due to have a TVT and anterior repair and had previously been interviewed as a general case. She re read her previous interview and made additional comments, which follow the original interview below.

Her problems started with stress incontinence 10 years ago when she had her second child. She thought it was because of childbirth and her doctor said she had had two babies in a short distance. She had two more children and just put it to the back of her mind. Stress incontinence got progressively worse and she told the doctor she had problems down below. She had a prolapse, a cystocele and rectocele and was referred to a gynaecologist who told her she needed surgery. She had an abdominal hysterectomy bilateral salpingoophorectomy, anterior repair and colposuspension and later that year a posterior repair.

She was fine for about two years and then the prolapse came back. She tried to put it out of her mind and saw the GP. She was referred to a gynaecologist and had bladder pressure studies done. He told her he could not do anything for her and referred her to a urogynaecologist. The urogynaecologist told her she needed the repair and she wasn't emptying her bladder properly.

She thinks when your mind is on other things you don't always think of the toilet. Sometimes she just soaks and she has to find out where the toilet is. Her kids say 'why are you going to the toilet again?' She wears pads out but not around the house as she finds it uncomfortable wearing them all the time. She drinks less but drinks more if there are toilets in the vicinity. She goes to the loo before leaving the house, even if she has been half an hour before. She has stress incontinence having intercourse but doesn't often have intercourse, as it is too painful.

She drinks less when out. When on holidays she knows where the toilets are. She carries pads and underwear in a vanity bad. Sometimes she wets herself. She wears two pairs of pants if going out for an extra bit of support.

She says the surgeon thinks the repair might do it. The bladder scan showed there was extra left. They gave her the option of taking Prozac but she wouldn't take that. If she is distracted by something she can leak.

One minute she wouldn't want to go, other times she could be busting to go. When she is pulling her pants down she is soaking. Otherwise, standing up after a wee, she stands up and is soaking.

She finds it embarrassing with the kids who say *'Mum why do you have to go to the toilet again, you've just been'. I used to play football with them; I can't do that now, unless I put three pads on. Sometimes I feel as though I smell. Probably I don't but…'*

She hates going swimming, because if she is in the pool for an hour she has to get out 15 times. She wees before a shower and straight after on the floor. No matter what she does. She doesn't know why. She tends to drink a lot more fluid at home because she doesn't drink much when out. At work she may have one drink in 10 hours, because she doesn't want to be wet. At home she can have a shower. A couple of times at work she had to have a shower and pretends it is to cool off.

She is very sympathetic with the gynae patients. Those for TVTs, '*I listen to them and I think 'God, that's just me'. We are all funny bodies'.* Working night shift has no effect on the bladder. On her days off she doesn't leak as much. She goes to the toilet even if she doesn't need to go so she doesn't wet herself. She doesn't wait until she wants to go and is not sure if you should or shouldn't do that. She heard that cycling helped the bladder and cycled 12 miles yesterday and didn't leak.

She doesn't want tablets. HRT is the only one she takes. She has backache and I wonders if it is the prolapse, bladder or wear and tear. With the first operation she thought that would be it sorted out. She was very big when she got pregnant and put on a lot of weight each time she was pregnant.

She is relieved to be having another operation. Walking from the car park she gets aches and pains and wants to sit down. She gets stress incontinence and leaking and it is irritating more than anything. If she goes out to a pub at night she has to know where the toilet is before she gets a drink. She always carries toilet paper. It stops and starts. She doesn't like using public toilet paper because of the prolapse. Last year she got thrush a few times. Now she doesn't go to the GP but gets canestan from the chemist and takes it on holiday.

At second interview (Have you anything you would like to add about the bladder problems or your life in general?)
No, just the same. So cautious of yourself all the time.
(What are you expecting of the operation?)

That I won't be wetting myself. I won't have to wear pads. I've worn them so long, I'd be conscious. I'd put them in probably *(laughs)*

(Is there anything else you feel about surgery?)

I worry that it is going to be a temporary thing, rather than a permanent, 'cause I had it before. I dread going through all this if it's not going to be a positive result.

(Anything else at all?)

No

Urodynamics

Preoperatively there was moderate to severe USI with borderline flow so ISC was taught first. Postoperatively there was a small leak with three coughs but no leak with five coughs. There was slight provoked DO with a desire to void but no actual leakage.

Kings Health Questionnaire

Domain	Preop Score	Postop Score
General Health Perception	50	50
Incontinence Impact	100	66.67
Role Limitations	100	50
Physical Limitations	100	50
Social Limitations	88.89	44.44
Personal Relationships	83.33	50
Emotions	66.67	44.44

Sleep / Energy	50	50
Severity measures	100	66.67

Assessment of subjective success of surgery for stress incontinence

She feels her operation has been very slightly more successful than unsuccessful (scoring 5.9 where 0 is not successful and 10 is completely successful). She is very slightly more satisfied than dissatisfied (scoring 5.5 where 0 is not satisfied at all and 10 is completely satisfied). She feels fairly happy (scoring 7.55 where 0 is very unhappy and 10 is very happy). She feels very relaxed (scoring 0.5 where 0 is very relaxed and 10 is very tense). She very rarely leaks (scoring 9.1 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grid

She would like not to be wearing pads. Her hopes and expectations for after surgery are identical. She is now after surgery how she hoped and expected to be in relation to not wearing pads is similar in relation to feeling less self-conscious. She feels some benefit from surgery but not as much as she had hoped or expected. Her activities are more restricted because of time and fluid restriction than she hoped or expected. She has a lot more urinary frequency than she expected and nearly as much as she had when her bladder was at its worst. Her freedom is a lot less than she had expected and nearly as poor as when her bladder was at its worst. She likes walking, attending kids sports activities and running and associates them with

pleasure, freedom and fun. She does not like shopping, gardening and hoovering and associates them with manual, necessity and boredom.

Situations affected by incontinence

Her UI causes/caused her the most difficulties with a lack of freedom, due to frequency, embarrassment when incontinent, needing to know where the toilets were, buying pads and reducing fluid intake at times. UI is less of a problem to her when she is at home, knowing where the toilets are, when she has someone with her, no children around her or persons who she is with knowing her problem. She does not now wear pads or any extra protection.

Postoperative interview summary

She describes urgency '*I can't hold the wee; when I have to go I have to go. Just can't. Often have to double void. I could do a wee and in half an hour go back when I want to go I'd get this terrible pain discomfort. Maybe that's what's meant to happen I dunno'.*

Originally she was very disappointed as she had a catheter for 2 ½ weeks because of high residuals. It didn't seem like it was straightforward. She found It embarrassing going home to the kids with the catheter for two weeks. She was housebound for two weeks with the embarrassment of having to do ISC three times a day.

She still restricts what she drinks, where she is going and wonders if there is going to be a toilet there because she knows she wouldn't be able to hold her wee.

‘*So, the only benefit 100% is that I don’t leak, that, so that’s it’*

In relation to her preoperative interview

1. Do you still feel cautious of yourself all the time?

Always

2. Have you stopped wetting yourself?

I have, yeah

3. Do you still wear pads?

No

4. Do you still have episodes of soaking?

Well I’ve had two since my op because I wasn’t in the vicinity of where a toilet was

5. Do your children still comment ‘why are you going to the toilet again’?

No they don’t ask now

6. Do you still restrict your fluids? When you are out? At work?

Yes

7. Do you still go to the loo before you leave the house? Even if you have been half an hour before?

Yes

8. Have you had intercourse since the operation? Was there stress incontinence? Was it painful?

No

9. Are you still aware of where all the toilets are?

Yes

10. Do you still carry pads and underwear in a vanity bag?

Still carry underwear, not pads. The extra thing I carry is wipes to wipe the toilet seat before I use it when I'm out since I had two UTIs. Maybe I'm just a fanatic. (Did you carry wipes before?) No. (So that is extra?) Yes.

11. Do you still wear two pairs of pants if you are going out? For extra support?

I've only done it once to go to a football match 'cause I didn't know if there would be a toilet about. But I managed to hold for 2 ½ hours and wasn't bursting when I got home. I was proud of myself. I only drank one cup of tea and had to drink more after

12. You said before that sometimes one minute you wouldn't need to go to the toilet and the next minute you could be busting to go. Does that still happen?

Yes. Same as.

13. You used to be soaking when you would be pulling down your pants. Is that still happening?

Not as often. It does happen but less often.

14. What about when you stand up after a wee? Would there be a leak?

No that's gone

15. Are you able to play with your children now? E.g. football. (Do you put 3 pads on to play with them?)

No. well I just haven't tried to be honest

16. Do you still worry in case you smell?

Not as much

17. Have you tried going swimming? (If not, would you try?)

No. I would yeh. (Just not yet?) No

18. Do you still have a wee before you get into the shower?

Yes

19. What about after the shower? (Used to wee on the floor)

No, not really. That doesn't happen anymore. The leak seems to be gone

20. Have you had to take a shower at work because of leakage?

Not back at work yet

21. Do you still go to the toilet when you don't need to go? (To avoid wetting yourself)

Well. I double void because I just feel uncomfortable after and half an hour later, and wee more than ½ hour earlier. If I was going somewhere, for piece of mind

22. Do you still get backache?

No

23. Do you still feel irritated? (About the leaking and aches and pains)

Not with the leaking 'cause it's gone. Not a problem.

24. If you go out to a pub, do you still find out where the toilets are before getting a drink?

Yes, I would. I went out Saturday night and I drank two glasses, which is, what, 400 mls, and I had to wee five times in two hours.

25. Do you still always carry toilet paper?

Yep. Not toilet paper, wipes, wet wipes. (That is for the toilet, or for you) for the toilet and myself.

26. Will you now use public toilet paper? (Did not before because of the prolapse)

No

27. Have you had any more episodes of thrush?

No

I'm pleased I had it done; I'm just hoping the outcome is going to be better. If not I'll have to get the padding. I just feel my bladder doesn't hold the amount of wee as before. I was out and I could hear this women weeing and thought I wish I could wee like that. It tends to dribble and think I'm on the toilet for about 15 minutes. I probably am.

(What is the best thing about the operation?)

No stress incontinence

(What is the worst thing?)

Having to wear the catheter for 2 ½ weeks.

(If you had a friend who told you she was going to have this operation, what would you say to her?)

At this moment, she wants, well. I'd say I'm not fully recovered. I'm hoping things will improve. Just 'cause I'd a catheter for two weeks doesn't mean you will. Just 'cause I'd two UTIs doesn't mean you will either.

(Okay is there anything else?)

I just hope this frequency will improve or I'll hang myself

Case study 8

Preoperative repertory grid

She would like to be able to dance after the operation. Her expectations are not has high as her hopes for after surgery. Her constructs are being able to sneeze without leaking, not feeling embarrassed, being sociable, able to dance, feeling confident and not being conscious of the bladder at work. She does not expect to be as good as she was before the bladder problems started in these respects. She enjoys reading,

socialising and shopping with her daughters. She does all these for pleasure and they make her happy. They vary from each other in the other bipolar constructs, which mostly relate to physical exertion (and are involves walking, do it by ones self/social, choosing to walk, exertion.) She does not like exercise, walking and running and her constructs are mostly related to exertion and not choosing to do these.

Situations affected by incontinence

Her UI causes her the most difficulties if she leaked in a situation that she cannot change her clothes, if someone notices that you have leaked i.e. wet clothing, if she sneezes or coughs when with a customer, at conferences where she is not able to leave the auditorium and has to dance to be seen as sociable. UI is less of a problem to you at home, with her immediate family, husband and children, on her own, relaxing and when she is prepared for leakage. She wears one to five Tena lady (sanitary towel size) per day to protect clothes and to prevent soaking and odour issues

Preoperative interview summary

Her problems started when her children who are 17 and 15 were babies. She thinks she is probably the same as everybody. She got referred and advised to use the cones but hadn't time, with a baby, to walk around the house with cones and couldn't be bothered. She struggled on and on and then something dropped that broke the camels back. '*You just accept it and get on with daily life. It's not an illness, that's how I perceive it. It's an inconvenience but I'm not ill.'* She explained how she leaked

on holiday, with her sister, her husband and children. They were in a lift and she had a summer skirt on. They had a laugh and the urine was running down her legs. Her brother-in-law said ‘ha ha, look’. She went to her GP thinking she can’t put up with this anymore.

She wears a uniform at work and she can’t wear the trousers for two days or more. If she is at a conference she is worrying all the time about where the toilet is and she travels a lot. She is okay at home.

She is having a colposuspension and thinks, why is she putting herself through all that when she is not ill. She spoke with the girls at work about it and they have put it in perspective that her quality of life will be so much better, if it works. She can’t imagine not leaking now; it’s a way of life.

She wants to know if it is worth the end result because she is not ill and is young. She explained that she goes away with strangers on educational trips and shares a room. People who don’t know her think that she is being miserable if she doesn’t dance.

‘The thought of not leaking is absolute bliss. I can’t imagine not leaking. I am a manager. I run a team of 10 and I believe we should have a happy environment. We stand and laugh and I have my legs crossed. After I am going to stand like this (stands up with arms out and legs apart). Because I can. People make jokes. I know

they are only joking but it still hurts and is embarrassing, but I don't show it, I just laugh.'

On conference she has to take enough trousers for everyday. She recently had to take an outfit for every night.

She had a hysterectomy when she was 32 and even though she doesn't have periods she still has to wear pads. When she had her hysterectomy she did mention it. *'While you're down there could you fix that at the same time?'*

One thing that stopped her seeking help was people thinking she has had a hysterectomy, now something else. She hasn't told some of her friends she is having it and finds the whole thing embarrassing. She feels that if it works she'll be the happiest person alive. '*I think it will affect my life more than I think it will. Because you have the problem you get used to it. It would be nice to be free of it. You should get a tape recorder to save you scribbling away.'*

It affects her clothes, the social situation, the inconvenience, to a certain extent the cost. Her daughters might be play fighting or tickling her and she tells them to stop in case she leaks. She has a problem where certain things make her sneeze and she sneezed in a restaurant with her daughter and leaked and still had to go to the cinema. She is lucky her family takes no notice but it holds her back.

She fluid restricts. She says that physiotherapy felt her pelvic floor wasn't working because she was holding it tight all the time, unconsciously, because she is conscious all the time of leaking. She needs to release it. She'd never run anywhere for anything because she knows it would be an absolute nightmare.

Her GP referred her to the hospital and said you don't have to put up with it and she was quite young. Her mum had a TVT when it was new. She already had a hysterectomy and didn't want to be seen as *'here she goes again'.* With the hysterectomy she was ill. With this she is not and it does affect her quality of life probably as much. She doesn't feel physically unwell and to her an operation equals illness and she is not ill but can see the benefit of having it. If it does work it could be the best thing that ever happened to her. She'd never have an operation for the sake of it. She can't understand people having cosmetic surgery unless their ears stick out and it's affecting them.

She just can't comprehend that she is going to be jumping, running, cracking jokes, standing there.

Things about it drive her mad. She can go to the toilet, and leak when standing cleaning her teeth and *thinks 'how can I be leaking, I've just been to the toilet'*

Some days she hardly notices it and others it will drive her insane.

After surgery she doesn't have clear expectations because she heard her friend's mum had it done years ago, it was the best thing she ever did. Her best scenario is she will never leak again for the rest of her life but she doesn't know. She says she is not a medical person so she doesn't know. The reason she went for the colposuspension was because the long-term effect of the TVT is not really known and if she is going to have it done she only wants one thing done. She knows she could have the TVT and if it doesn't work have a colposuspension. She doesn't know if she is doing the right thing. She asked me not to tell her surgeon that. She had asked him to help her decide and he could only advise her and she found that really hard because she has chosen the hard one. She knows two people with TVT, one who thinks it was the best thing and one who thinks it was a waste of time.

She says if she comes out okay and recovers she'll be okay on the other side. No pain, no gain. It will change her life dramatically. She was worried today because of the unstable bladder. Today they are saying is it because her bladder is seizing. She wonders if it because they don't believe her or think she is blagging it. She says she wouldn't do that and asked me not to tell them. She asked if they do not believe she leaks as much as she does. She says they are staring at the screens and saying technical stuff she doesn't understand. Today she did not leak as much and she has been walking around the car park and everything. Whether it's because she is more conscious with the tubes in.

She wouldn't put herself through that if she didn't think it was necessary and making her life an absolute misery and she has got to that stage. She felt much happier

about the first test she had. '*Obviously it was really indignant. Mr_____ (urogynae) said 'stand and cough' and it goes ppssssh, you know. I was embarrassed. But it showed the problem. Today I felt maybe they don't believe me, do you understand what I mean? Like I say, I can't believe anybody will go through that if, em.'*

She did feel a bit better because she saw Mr _____ (urogynae) last week and he felt that the colposuspension might help her small prolapse where the TVT wouldn't.

'*The best scenario will be if I come out of it and am free for ever or even till I am 70, 'cause I wouldn't care then would I?'*

She knows there are risks and she might have voiding difficulties. She says she is not stupid and is prepared to take the risks. She is not going in with her eyes closed. She is a bit worried and people say different things. She is going away for her 40th six weeks after surgery. Mr_____ (urogynae) says its fine, others say she is at risk of deep vein thrombosis and she is worried. Her GP said two weeks off work. Mr____ (urogynae) said six weeks and the nurse said 12.

She will be driving straight after as well. She knows you are not really supposed to but she could not not drive for six weeks. '*I've got to go on that holiday. I'm going on that holiday. I'll be great, laughing, sneezing, coughing, dancing the night away. It will be a milestone; I'll be 40, the best birthday present anyway.'*

Urodynamics

Preoperatively USI was demonstrated. On ambulatory UDS there was a possibility of DO raised but it was felt unlikely as it was not symptomatic. Postoperatively urodynamics was normal.

Domain	Preop Score	Postop Score
General Health Perception	25	50
Incontinence Impact	100	33.33
Role Limitations	66.67	16.67
Physical Limitations	66.67	0
Social Limitations	44.44	0
Personal Relationships	0	0
Emotions	88.88	44.44
Sleep / Energy	16.67	50
Severity measures	93.33	20

Assessment of subjective success of surgery for stress incontinence

She feels there has been some success with her operation (scoring 7.6 where 0 is not successful and 10 is completely successful). She is fairly satisfied with the outcome of her operation (scoring 8.4 where 0 is not satisfied at all and 10 is completely satisfied). She feels reasonable happy at the moment (scoring 8.1 where 0 is very unhappy and 10 is very happy). She is feeling relaxed (scoring 1.8 where 0

is very relaxed and 10 is very tense). She still has some leakage (scoring 8.3 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grid

She is able to sneeze which she could not do before the operation. She had a much longer recovery time then she was expecting. Regarding leakage she is how she expected to be but not as good as she had hoped. She is able to sneeze and is as good as she hoped and better than she expected. She is able to dance, has very little urge and is quite relaxed rather than worrying about leaking.

She likes watching the television, going on holiday and shopping. She does these through personal choice; they are social and a routine. She does not like working, exercise and dieting. She needs them to be fit but finds then not pleasurable. Her construct s are pleasurable/not pleasurable, go out to do/in the home, personal choice/must, needed to be fit and healthy, social, something she would/wouldn't normally do

Postoperative situations affected by incontinence

Her incontinence causes/caused her the most difficulties at work if she can't get to toilet in time, shopping if no toilet is near, in the car as she can't get to the toilet and in the early morning with urge incontinence. Her incontinence is less of a problem to her sneezing, coughing, laughing, dancing and walking/running. She does not wear pads or any extra protection.

Postoperative interview summary

She thinks the operation was absolutely fantastic and on the whole she is really pleased with the results. She is 95% dry but still has the odd incident where she leaks for no reason and she doesn't really understand why because it didn't happen before, but it's very little and it's bearable.

She is a bit disappointed with the recovery time and she wishes she knew more. She was told it was a major operation and was told six to 12 weeks but it is about 15 weeks and her scar is still sore and she doesn't think her fitness is anywhere what it was before. She does expect it to improve and doesn't think it is a problem.

'*Generally I'd say I'm over the moon with the results really. When I was talking about the incontinence I was going on and on and on.'*

Her quality of life is better as she can sneeze and laugh without leaking things people take for granted who don't have incontinence. She doesn't wear pads anymore. Because she had a hysterectomy she used to really begrudge the fact that she'd to wear a pad. It's more convenient 'cause she doesn't have to change. She can wear her trousers more than one day in a row.

The embarrassment of being wet unexpectedly has gone, feeling the dread in case she does wet herself has gone.

Related to the pre-operative interview:

1. Since the operation have you had any incidents where the urine has been running down your legs?

Yes. (What happened then?) Just started, em, just started on its own, no reason, nothing to trigger it. I just assume that the bladder is full. I have a couple of days where it happens three times in a day and it may not happen for a few days. I get the odd day where I leak and leak and I don't know why.

2. Do you still leak?

Yes

3. Do you think you will be able to wear your work trousers for more days then before?

Yes

4. How do you think you will manage at a work conference?

Great, laugh

5. Do you worry about where the toilet is (all the time)?

Em, yeh, I do. That hasn't gone really. In fact I probably worry about that more now. (Do you know why?) Because I relate this leaking to the fact I have a full bladder. Whereas before I thought if I sneeze I leak. I am hoping what is happening is the bladder is too full and I just can't control it

6. What about not dancing on conference and other peoples opinions of you?

That will have changed 'cause I will dance now. They won't think I'm miserable anymore.

7. How do you feel about leaking/not leaking?

I feel great about the fact that the vast majority of the time I don't leak anymore. It is occasionally rather than all the time. It is not a daily event. It is a weekly event or a monthly event. The only thing I will say is now it is an unexpected event where as before I knew if I was going to sneeze I would be wet.

(Which is worse?) Definitely before *laughs.* No contest. Before it is everyday of my life and I can put up with that and I'm sure that can happen to anyone, who hasn't ever been incontinent. It can happen to any of us. I have put on loads of weight since the operation and I can go for a walk everyday. I can walk and walk, no problem. That is the other thing I am thinking, is the extra fat pressing on my bladder causing these occasional mishaps 'cause I have put a lot of weight on.

8. How do you feel about your team at work now? Can you stand and laugh now?

Yeh. Mind you they have just given me a bloody load of trouble now and I hate them all. But I can laugh. When I was in hospital, they sent me a picture of the toilet saying it is missing you! I laugh and say 'it might be you now, mine is fine'. The other day it was about three o'clock and I said 'look my bladder has held out all day and no leakage.

9. Do you have to pack a lot of clothes changes for trips now? In case of leakages. An outfit for every night?

No. no. I used to take my husband, a standing joke, for a 7 day trip, I took 21 pairs of pants in case I might need 'em. I wouldn't do that, I wouldn't worry so much now.

10. Do you still have to wear pads?

No

11. You were concerned because you had an operation before that people would think ‘oh. My god what now’. Have you had any reactions like that?

Not really. No

12. What about your friends? (You hadn’t told some of them about the operation)

Em, no, everybody knows. The only thing that worries me now about the op is I don’t think everybody understands the extent of the op. she looks alright. Why is she still saying she is tired and sore, and I am? People don’t understand the recovery period. ‘Cause it wasn’t an illness, I wasn’t ill. People don’t understand and I find that quite hard.

13. You said you found the whole thing embarrassing? And now?

No, I’m not ill. They said you’ve got to have it done, why put up with that. So no, I don’t anymore

14. Do you feel happier since your operation?

Nods. Yeh.

15. Has the operation affected your life? In what ways

Yep. Better quality of life as in not embarrassed, not worried. Got more freedom to do what I want to do. More convenience. Don’t have to change clothes. Do things I couldn’t do before ‘cause I couldn’t. More comfortable. Less anxious. Am I going to wet myself today.

16. What about clothes?

I can wear my clothes layer, sounds disgusting, you know what I mean (yep). There used to be times I’d have to get changed an hour after changing. I still can’t get into my clothes! I have to wear skirts still can’t wear trousers, whether I am still uncomfortable.

17. What about social situations?

Good, really good.

18. What about the inconvenience?

There is no inconvenience now really

19. What about the cost (of buying pads?)

Same

20. How has it been with your daughters? Before you would worry if you were play fighting, in case of leakage. Or if they were tickling you

Much better

21. Could you run?

Yeh. In fact, my daughter commented. We ran for a train. She said ‘mum, I’ve never seen you run before!’

22. What if you sneeze?

Sneezing is the best thing ‘cause I have an allergy to food and I may sneeze for 10 minutes. I can sneeze all day and no fear of leakage.

23. Do you feel your bladder holds you back with your family?

No

24. Do you still restrict the amount you drink?

No

25. Do you still think you are holding your pelvic floor all the time or do you think you are relaxing it?

I probably think I’m still holding it through habit. I still get that urge to sort of clamp if you like if you cough or sneeze. I suppose it’s been such a long time.

26. Are you worried about leaking?

No

27. Do you still feel humiliated about your bladder?

No

28. Do you feel there was a benefit to having the operation?

Oh, absolutely

29. Do you feel the operation has worked?

Yes

30. Are you able to jump, run, crack jokes?

Yes

31. Do you leak when brushing your teeth after going to the toilet?

No

32. Does your bladder still drive you insane some days?

No

33. Your friend's mother thought the operation was the best thing she ever had and you knew of someone who thought it was a waste of time. How do you feel about that now?

Em, I agree with the one, it is fantastic. I don't regret it at all.

34. How do you feel about having the colposuspension instead of the TVT?

Em, I wished I would have been better prepared for the colposuspension. I don't think I totally realised the size of the operation and the after recovery. There have been days I've said 'I wish I never had it done', 'cause it took so long to get over it. There was another girl in the same day. We are both in agreement that we wish we had known more. I am glad I had the colposuspension once I am over it. With TVT I don't know if I would have trusted if it would have worked. You don't want to scare people

to death. To be fair Mr___ (urogyn) did say it was a big operation but I don't think I was truly prepared. I think my hysterectomy was a walk in the park compared.

(What do you think we should tell people?)

It is hard as you don't want to frighten people to death. Maybe tell them to expect a long recovery period. Even though I am back at work I still feel very tired. But I have talked to ___ (other patient) and she feels exactly the same. It is only a few days ago I could walk. I have only gone back to work and doing reduced hours. I was led to believe six weeks and maybe up to 12. It is hard 'cause I don't want to scare people and I know once I am over it and that is it for my life. It may have altered my decision. I may have given the TVT a go. But then that wouldn't have fixed the prolapse either so. That sounds very ungrateful but I don't regret it. I just wish I was more prepared for it maybe.

35. Do you feel that you have recovered okay?

Em. Not at the moment. No. Still have days were I feel like my insides are going to drop out. Still very sore, very tired. Not as much stamina as I had before.

36. You were concerned during the ambulatory test that they perhaps did not believe your symptoms. How do you feel about that test now?

No. well, they said to me if I had the operation and it wasn't truly necessary it could go the other way with urge incontinence and yes, I do get the occasional urge and to be honest I must have needed it. If there was nothing to be done I would have had the results. There must have been a problem.

37. Do you feel free now (of the bladder problem?)

More or less

38. Have you had any voiding difficulty?

No

39. Do you feel that you were aware of the risks involved in the operation?

Yeh, I was aware of the risks

40. You were concerned about your recovery time and your trip. How do you feel about this now?

My trip was fine. Probably not as fit as I would like to have been but I expected that really.

41. How soon after the operation did you drive? How was it?

About 4 weeks. Em, to be honest I would say driving was one of the worst things. I probably shouldn't have but at that point I was so sick of being in the house. I think I was in my pyjamas! I couldn't walk but I found driving very uncomfortable. Pushing the pedals and the belt. But it didn't stop me. Naughty!

42. How do you feel about laughing, sneezing, coughing, dancing.

Fine

(Are you pleased or regret having the operation?)

Oh no, pleased

(What was the best thing about the operation?)

Being dry

(And the worst thing?)

The recovery time

(If a friend was going to have this done is there anything you would say to them?)

It would depend on how severe it is in the first place. I'd tell her without doubt to have it but be prepared for the first few weeks after. I'd tell her wholeheartedly to have it

done. It changes you life but warn her. In fact I have told someone to have it done. Someone who had had an unsuccessful TVT.

Case study 9

Preoperative repertory grids

She would like to be able to run. She hopes to be slightly better than she expects in the following constructs: able to do exercise, carefree, no leakage, fear about surgery and fear of smell. She does not expect to be as good as she was before she had bladder problems in respect of any of these constructs.

She really enjoys walking with her husband, salsa classes and drinking socially. These are pleasurable, refreshing and not part of her job. She hates confrontation, rudeness and lies and these do not involve her husband, are not exercise, are unpleasant, antisocial and are more part of her job.

Preoperative situations affected by incontinence

UI causes her the most difficulties joining classes with activity in them, sneezing and coughing, during intimacy and playing with her grandson. It is less of a problem to her in inactive situations, with people who know she has a problem, in strange places where location of loos isn't apparent and relaxing at home. She uses three to four sanitary towels or tena lady per day to protect clothing and to worry less about anyone else knowing.

Preoperative interview summary

She didn't really recognise that she had a problem because she thought it was normal when people sneeze, cough or laugh '*cause you often hear people say 'don't make me laugh, I'll wet myself'*.' She found as she did more walking she'd be prone to urgency and it felt like there was a bubble about to come out her vagina that would burst. It did burst and she sought help from her GP. She was embarrassed. Her GP was reassuring and suggested physiotherapy. She used exercises and cones, which was helpful initially. She bought her own cones and continued to exercise, perhaps not as often as she thinks she ought to have. It got worse, any activity, reaching the top of steps. Where she works there are loads of doors, which need a combination and if she doesn't know the combination and pulls on the door, it would cause a leak.

Being intimate with her husband was embarrassing. She didn't realise what was happening to that extent because there are obvious pressures in that area, that was disturbing. The final straw was when a colleague jumped out and she had more than a leak, it was embarrassing, she thought, '*this has gotta stop.'*

She thinks it is a relief to know there are more women than you think have the same problem. It is almost an unspoken problem that people keep to themselves because it's embarrassing. One of her colleagues enquired why she was off work. Her husband told her and she said she had the same problem and was offered the operation but was too scared to have it. She is a younger woman. She thinks it's a shame that it is not talked about as it could be and it's hidden. '*Especially as this operation can hopefully make things a lot better.'*

Her husband says it's not just a women problem but you think it is because of the reasons like forceps delivery and being overweight, but it's not just a women's problem. She found out that her mum was having similar problems. She died 18 months ago. She wouldn't speak to her or her sister but she spoke to her daughter, which she found bizarre. She was terribly overweight, her son was 12 pounds when he was born. It was maybe a combination of her weight and a large baby. She never spoke about it, because it could have been reassuring for her as well as her.

Sometimes she feels less of a woman, because she tends to wear cotton knickers that can be boiled and big knickers because they are more practical. You lose the choice of being, vanity or not, a little more glamorous. She doesn't want to accept it as part of her life. It isn't acceptable.

She will just be glad the surgery is here. She is not expecting perfection but just for it to be better than it is now. She is trying not to expect great things because she doesn't want to be disappointed. If it is better than it is now and surgery stops the problem, that will be perfect. If she is able to live her life like she used to, even if it is just better, that would be great too.

She described a very embarrassing situation when she was cycling with her husband and grandson. She wasn't concentrating and hit a pothole, causing her to fall off her bike and lose all control. The lady whose house they were outside of, came out and offered her tea and sympathy and all she wanted to do was get home and showered

and sorted out. She was in pain with her knee but having to explain that to her grandson, she just couldn't.

She is just wanting for things to get better.

Urodynamics

USI was demonstrated preoperatively. Urodynamic studies were normal postoperatively.

Kings Health Questionnaire

Domain	Preop Score	Postop Score
General Health Perception	25	0
Incontinence Impact	66.67	33.33
Role Limitations	66.67	0
Physical Limitations	50	16.67
Social Limitations	44.44	0
Personal Relationships	33.33	0
Emotions	100	0
Sleep / Energy	50	16.67
Severity measures	86.67	0

Assessment of subjective success of surgery for stress incontinence

She feels her operation has been somewhat successful (scoring 8.5 where 0 is not successful and 10 is completely successful). She is reasonably satisfied with the outcome of her operation (scoring 8.5 where 0 is not satisfied at all and 10 is completely satisfied). She is very happy (scoring 10 where 0 is very unhappy and 10 is very happy). She is very relaxed (scoring 0 where 0 is very relaxed and 10 is very tense). She still has some leakage (scoring 8.7 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grids

She can now confidently walk from work to Birmingham. She is better than she hoped or expected in all her bipolar constructs - a new lease of life, good, confident, reality, no fear, and normal. She scores the same scores on all of these, for how she was before the problems started, except for a new lease of life, for which her score is even higher postoperatively.

She likes walking, socialising and gardening and she associates these with activities, a personal choice, caring and not angry. She does not like idleness, lies and ignorance and to her these are not an activity but are still a personal choice. She associates them with being not enjoyable, uncaring and angry. One of her constructs was related to doing things alone or in company and scores varied across elements.

Situations affected by incontinence

Her incontinence causes/caused her the most difficulties sneezing and running (slightly). It is less of a problem with strident walking, during intimacy, coughing, with

surprise/shocks/scares and socialising, worrying about smells etc. She no longer wears pads or any extra protection.

Postoperative interview summary

It has been like a new lease of life. She feels more confident, happier in herself, as though a weight has been lifted. She has said to colleagues, it has been a life changing experience. She wishes she had known about it sooner, because she'd have done it sooner. She just feels totally happy about the whole thing. Her daughter didn't realise how bad it had been and she has seen a whole change in her demeanour. Her husband didn't realise how bad it has been, but it's definitely life changing.

In relation to her previous interview.

1. Do you still leak if you sneeze, cough or laugh?

Em, not always.

(Sometimes?)

Sometimes a sneeze will catch me out if it is vigorous. I still prepare myself and cross my legs, but I think it is just a habit.

2. If you are walking do you feel like you need to go to the toilet quickly?

No

3. Do you still get that feeling that there is a bubble down below that is going to burst?

Em, very rarely. In fact the one occasion I'd walked to town and I came back and it felt like the bubble had burst but it was negligible in comparison to before the surgery.

4. Are you back at work?

Yes

Have you had any leaks trying to open the combination doors at work?

No

5. Do you still find being intimate with your husband embarrassing?

Not any longer, no.

6. Do you remember you told me you had a large leak when your colleague jumped out at you at work? Has anything like that happened since the operation?

The surprises. That has stopped as well.

7. Have you found you have been able to speak about the bladder problems more now?

Yes, very much so.

(What do you think about that?)

It's liberating.

8. Do you still find it an embarrassing thing to talk about?

No. Not any longer. No.

9. Do you feel the operation has made things a lot better?

Definitely, yes.

10. You told me before that it made you feel like less of a woman. How do you feel about that now?

Em, it did then. I feel, I have bags more confidence and am back to normal.

11. Have you been able to wear different underwear other than the big cotton knickers you used to wear?

Yes. *Laughed.*

12. You felt your situation was not acceptable. How do you feel about that now?

Em, I still agree with that. Incontinence, incontinency is not acceptable but it's the ignorance that's the worst 'cause I didn't know it existed, the operation existed I mean. I've never seen anything advertised in my doctors but my daughter registered with a new GP and there was a leaflet there about a TVT. Having said that, I'm not at my surgery much, but I've never seen one there, there was one at my daughters.

13. Has the surgery stopped the problem?

Em, to a great degree, yes.

14. Do you feel you are able to live your life like you used to?

Yes. Definitely

(Are you pleased or do you regret having the operation?)

Do you have to ask!

(*Nods)*

Very pleased. Very, very pleased.

(What was the best thing about having it done?)

Em, surprisingly it was painless. The whole thing from the beginning to the start, from the operation to the recovery has been painless with great results.

(What was the worst thing about having it done?)

Fear of it not working

(If a friend told you she was going to have this operation. What would you say?)

Great. Good for you.

(Is there anything else you want to add?)

I work with a colleague who had a hysterectomy that has caused her to have incontinence. It was discovered that he was not a doctor, he was a quack. Her bad experience has put her off but she is thinking of a TVT now, so that is positive.

The operation itself was quite bizarre, being awake. The anaesthetist, Dr___ (anaesthetist) was quite entertaining. It wasn't Mr _____ (urogynae) who did it, it was a lady doctor and he was shouting instructions at her. It was surreal. It was okay. The care was very very good.

Case study 10

Preoperative repertory grid

She would like to be able to go rambling. Her hopes and expectations for surgery are identical in relation to disability, normality, happiness and being watertight and the expectations for those elements are identical to before the bladder problems started. Her expectations are slightly less than her hopes in relation to improved and what is known.

She enjoys gardening, seeing her grandchildren and walking and constructs them to be happy, jolly, relaxing and enjoyable. She does not like grocery, cleaning and ironing. Constructs for these are not consistent. Her bipolar constructs and therefore the terms in which she evaluates these things are not pleasurable/pleasurable, not active/active, necessity/happiness, tiring/enjoyable, relaxing/stressful and boring/jolly.

Situations affected by incontinence

Her incontinence causes her the most difficulties when eating out, walking fast, dancing, coughing and running. It is less of a problem to her sitting down, lying down, standing still and slow walking. She wears 0one or two sanitary pads per day to absorb leaks.

Preoperative interview summary

She had a prolapse and vaginal hysterectomy in 1984 and it stems from that time. She understands when she went back to her consultant that they had done a small bladder repair. He advised pelvic floor exercises and sent her to the physiotherapist and explained in great detail about tightening up etc. The consultant gave her some pessaries to use, '*low dose, vagina something. Do you know them?'* She used the pessaries and did pelvic floor exercises and it was only marginally better.

Three years later she went back to Mr__ (retired urogyn) and asked if she could have an operation. She was only 50 something and it was disabling. She thinks she has got used to it now. He wouldn't recommend it. She presumes there was no TVT then as he said it was a difficult operation and he wouldn't recommend it for her. She sort of gave up on it then and kept on using the pessaries. Then she had an immune deficiency problem with her platelets and had blood samples but couldn't find any cause and it went away. She had her gallbladder extracted about 40 years ago and I wondered if it could be the pessaries. She stopped using them and the liver problems and the nausea seemed to clear up, she says it may be coincidental. She saw an article on duloxetine last year and showed it to her doctor and she gave it to her. It was a great help, not a cure, but a great help so she is on that at the moment. It

enables you to go longer between toilet breaks, which is useful if you are stuck and cannot find a toilet. She only recently went back and asked the doctor if she could have an operation and she told her about the tape.

Last week she saw a newspaper advert for Zuidex urethral injection for stress incontinence. She asked me if Mr__ (urogyn) does this as she was wondering if it was better. I explained it was available but not considered as good as TVT and discussed how she can have another appointment if she wanted to discuss this further. She said she was happy not to.

She got frustrated. Her husband had a heart problem but if he hadn't he would have been able to go on long walks. She thought in another 10 years she is going to be sitting in her chair being incontinent. It is an awful situation to be in. So she thought she'd make a move. There is this other operation which is a bit more complicated which Mr__ (urogyn) mentioned, which he wasn't recommending, the old fashioned operation. So whether that is the one Mr__ (retired urogynae) thought was not suitable. She asked how long the TVT has been around and said she could have come earlier really. She didn't want to stay on the tablet because she doesn't see it as a cure. They help by making it longer between but if she has to run for a bus she is still wet, or bending in the garden she leaks.

The leakage is restrictive particularly on holidays, on a tour or something. If you have to walk you have to control it so it does restrict your way of life. *'I mean I think I have*

stress incontinence – more, the other type, what's the name, just incontinence I think, can be more disabling. It is only when I do certain things that I leak.'

She wears a tight panty girdle thing, which is a great help in holding things up. She thinks all these little things help. She carries spare pads and has to remember that.

After the operation she has high hopes. She laughs. She hopes she will be greatly improved, maybe not a complete cure. '*It is not a 100 percent success is it? According to the leaflet, what does he put it at, 80%? Looks at the leaflet 90% of cases. That's quite high, isn't it?'*

She wants to be running for buses and if her husband gets better have longer walks, touring holidays. It won't affect her singing *laughs* 'cause she is standing still.

Urodynamics

Preoperatively moderate USI was demonstrated. Postoperatively urodynamic studies were normal.

Kings health questionnaire

Domain	Preop Score	Postop Score
General Health Perception	25	25
Incontinence Impact	66.67	0
Role Limitations	66.67	0
Physical Limitations	83.33	0

Social Limitations	66.67	0
Personal Relationships	33.33	0
Emotions	44.44	0
Sleep / Energy	33.33	33.33
Severity measures	53.33	6.67

Assessment of subjective success of surgery for stress incontinence

She feels her operation has been completely successful (scoring 10 where O is not successful and 10 is completely successful). She is completely satisfied with the outcome of her operation (scoring 10 where 0 is not satisfied at all and 10 is completely satisfied). She is very happy (scoring 10 where 0 is very unhappy and 10 is very happy). She is very relaxed at the moment (scoring 0 where 0 is very relaxed and 10 is very tense). She never leaks (scoring 10 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grid

She is able to walk five miles now. She is as good as she hoped she would be and better than she expected to be in her constructs feeling younger/older, no bladder problems/bladder problems, achieve less/achieve more, not feeling elated/feeling elated, not able to walk/able to walk. She is better now than she was before the problems started in relation to feeling younger and feeling elated.

She likes singing, gardening and walking. These make her feel better and relaxed, happy, pleasant, not stressful and not lethargic. She does not like getting up in the morning, ironing and arguments. These are not relaxing, do not make her feel better and are unpleasant and stressful

Postoperative Situations affected by incontinence

Her incontinence caused her the most difficulties walking (fast), bending down, coughing, sneezing and running. It is less of a problem to her walking long distances, bending down, looking for outdoor toilets, running and coughing. She does not now wear pads or any extra protection.

Postoperative interview summary

She thinks the operation was surreal and a bit strange as she has never had a local anaesthetic. The anaesthetist was very good and talked to her all the way through it. She incorrectly thought I was there. It was worthwhile and she was cured and has tested it, walked the 5 miles, bending in the garden. She was getting up two or three times in the night after the operation but it has settled down to one visit during the night.

When she starts passing urine it is like an orgasmic feeling. It makes her eyes run. She told her daughter who laughed. It is not stressful, it is just a sensation.

The operation was at 5pm and she was out the next afternoon. But another day and night in hospital would have been better, more restful.

In relation to her preoperative interview:

1. Have you been able to go on long walks?

Uh, huh. Yes.

2. If you run for a bus are you wet?

No

3. If you bend in the garden do you leak?

No

4. Do you still feel restricted by the bladder?

No.

5. What about holidays?

Well. It'll be much better won't it? I haven't had one yet. It gives me a wider choice if you like walking holidays and that sort of thing.

6. Do you still wear the tight panty girdle thing? Why?

I do, yes. To keep my tights up and warm. I suppose I shant in the summertime. (Did you wear them in the summer time before?) Yes. I have to get used to a different procedure now, after 20 years.

7. Do you still carry spare pads?

No

8. Do you think things have greatly improved since the operation?

Yes

9. What about a touring holiday? Do you think you could do that?

I do, yes, I do.

(Are you pleased or do you regret having the operation?)

Very pleased, yes.

(What is the best thing about having the operation?)

Eh, well to be dry really.

(What is the worst thing about the operation?)

I don't think there is really. It's for a good cause, so I suppose you have to go through those things but it was well worth.

(If you had a friend who was going to have this done what would you say to her?)

Go ahead. Yes, I'd thoroughly recommend it, yes.

Does it wear out?

(No. Not as far as we know)

I wondered if it wears out or drops down.

Does it grow into your flesh?

(Well, your flesh grows into it)

So it should be well supported shouldn't it? Em, er.

Case study 11

Preoperative repertory grid

She would like to be able to laugh and cough without leaking. Her hopes and expectations are identical to each other and to how she was before she had bladder problems except the construct what I had/what I am hoping for. Her other bipolar constructs are not proper lifestyle/proper lifestyle, not a normal life/a normal life, not wearing pads/wearing pads all the time, not nice being wet/very nice being dry, what I had/what I'm hoping for and miserable/happy.

She enjoys gardening, swimming and flower arranging which are mostly active, a good thing, lovely and please her. She does not like a dirty house, a dirty toilet or bad manners and these are inactive, a bad thing, horrible, unsocial and disgust her.

Situations affected by incontinence

Her incontinence causes her the most difficulties with chest infections, out shopping, out socialising, laughing and sneezing. It is less of a problem when in the house. She wears between none and three Tena lady pads per day to stop her clothes getting wet.

Preoperative interview summary

She can't remember the very beginning properly. She remembers being out at a party and was laughing and a big gush of water came out and she was embarrassed. It was years ago and she thinks from then on it was downhill.

She was constantly leaking and was in pads and it got worse and worse and you don't know when it is going to happen and she ended up at the hospital. She had a general leakage, not just with coughing and it got worse. Now she gets more chest infections and is soaking and if she laughs she is soaking wet. In a social situation or at home if she laughs she has to walk out and It's just one big embarrassment.

She can't wait to have it done and she hopes that it is successful. '*I suppose you call it desperation.'* She is disgusted and it is not something you say to somebody, you just sit on it, it's horrible.

After the operation she thinks things will be wonderful. If the operation works she is hoping she hasn't got to walk around in pads, coughing, sneezing, laughing and leaking, wetting. It would be good to sit in a room and have a good laugh and know she will not be wet.

She had a meal with last night with a lady who had a colposuspension and then this and is back to have her backside lifted up. She is really happy with what she had, which cheered her up. She thought she was a nurse the way she was talking but said *'no, I've had these operations and I know!'*

She says her husband will breath a sigh of relief if this works *'cause he knows how this affects me and how I feel.'* She will feel happy and relieved. She is hoping that this is the last surgery she has to have. The only other thing is how depressed she gets and she thinks that is part of it because she has terrible days, in a black pit down a dark hole and not being able to get out. She just cries and cries and she thinks that is all to do with the depression. She has good days where she is hopeful for the future since they have put her fluoxetine up. She is good at the moment and has had lots of different treatments for it. She thinks she has always been depressed from a child, always been the same. The bladder can make it worse, it gets her down and it doesn't help the situation.

She thinks another problem is her weight and she says she really needs to do something about it. '*You don't feel nice, you can't dress up. You are just on a downer with yourself and you don't feel at all attractive. My husband goes mad at me but it's how I feel and I can't help it, em.'* . She is going to try to take herself in hand and loose some weight again. She says she does that and then puts twice as much on again.

The only other thing is the arthritis. When you have bad days it's bad. When you have good days it's not too bad. It started in her feet and then affects her hands. They have put her on a new drug and eased it up, it is starting to work, but not the arthritis.

Urodynamics

Preoperatively she had severe USI and postoperatively urodynamic studies were normal.

Kings Health Questionnaire

Domain	Preop Score	Postop Score
General Health Perception	50	50
Incontinence Impact	100	66.67
Role Limitations	50	66.67
Physical Limitations	50	66.67

Social Limitations	88.89	22.22
Personal Relationships	33.33	16.67
Emotions	88.89	44.44
Sleep / Energy	66.67	33.33
Severity measures	80	53.33

Assessment of subjective success of surgery for stress incontinence

She feels her operation was successful (scoring 9.9 where 0 is not successful and 10 is completely successful). She is very satisfied with the outcome (scoring 9.6 where 0 is not satisfied at all and 10 is completely satisfied). She is neither happy nor unhappy at the moment (scoring 4.5 where 0 is very unhappy and 10 is very happy). She feels neither tense nor relaxed at the moment (scoring 4.7 where 0 is very relaxed and 10 is very tense). She suffers leakage (scoring 4.9 where 0 is leaking all the time and 10 is never leaking.)

Postoperative repertory grid

She can go out without a pad on. She is worse than she expected or hoped to be but not as bad as when her bladder was at its worst in relation to most of her constructs – urgency, bladder problems, ability to have a good laugh and perfect. She feels her hopes and expectations were more related to expectations than reality.

She enjoys gardening, flower arranging and swimming. These are relaxing, good, not irritating, pleasurable and do not disgust her. She does not like a dirty toilet, bad

manners and untidiness. These are not relaxing, irritating, bad, disgusts her, does not give her pleasure. She uses peaceful/energetic as a construct that varies also.

Situations affected by incontinence

Her incontinence causes her the most difficulties if she doesn't get to the toilet quickly enough, she can't stop it, at home and anywhere if caught urgent. Her UI is less of a problem to her in bed, laughing, coughing, being anywhere and being out. She does not wear pads or any extra protection.

Postoperative interview

She thinks her operation went well and she has felt a lot better since she had the operation. She just feels better not wearing pads and it's just nice to cough and laugh without knowing she is going to be soaking wet. Before it did affect her social life.

In company she used to try not to laugh because she knew what would happen. Now she can laugh and know she'll not wet.

The operation was what she expected and she was good with the recovery. Since the operation her only problems has been the urgency. She also wonders if it can cause backache as the past couple of weeks it has been really bad when she walks.

She is pleased with the operation.

Related to the preoperative interview:

1. Have you had any big gushes of water with laughing since the operation?

No

2. Have you had embarrassment because of leakage since the operation?

No

3. Are you still constantly leaking?

No. I'm not constantly leaking, no.

4. Are you still in pads?

No

5. Do you still have leakage that you don't know is going to happen?

Yes, I do. Because of the urgency

6. Do you still have general leakage?

Very slightly

7. Are you still soaking if you have a chest infection or cough ?

No, no. Well I've got one now, to be honest, so I've been doing a lot of coughing.

8. Are you still soaking wet if you laugh?

No

9. Do you still have to walk out of the room if you laugh because of leakage?

No

10. Is it still one big embarrassment?

No

11. Are you glad you had the operation done?

Oh yes.

12. Do you feel it has been successful?

Em, yes. I do.

13. You were feeling desperation before for the operation. How do you feel about this now?

Em, *intake of breath*. I'm not so bad now, no.

14. Do you still feel disgusted?

No, I don't.

15. Have you been able to say anything about the bladder to other people since you have had the operation?

Em, well obviously my family knows, but yeh.

16. Do you still feel you are just sitting on the problem?

No, I don't.

17. You said before that it was horrible. What do you think about this now?

Good. Yeh.

18. Do you feel wonderful now (since the operation)?

Em. I don't feel wonderful but I feel good. Just put 'good'.

19. Have you stopped walking around in pads?

Yes

20. Are you coughing, sneezing and laughing without wetting?

Yes

21. How do you feel now if you are sitting in a room having a good laugh?

I feel good now

22. Do you feel happy?

I feel happier than I was

23. Do you feel relieved?

I do feel relieved, yes.

24. What is the depression like now?

Em, can I do this on a scale of 1 to 10? I say at the moment the depression is about 4. I don't feel so bad now. (What has it been in the past?) On a scale of 1 to 10 it has been a 10. Moments when it has been very bad. I'm on antidepressants anyway now. I've been on them a long time.

25. Do you still get days were you cry and cry?

Rare now, rare. But this is how it can be Dr___. I can have a week were I feel quite good and all of a sudden you are stuck in a black hole but at the moment I feel quite good.

26. How do you feel about your weight at the moment?

Oh terrible

27. How is the arthritis at the moment?

My feet are bad and my hands are bad as well, a lot of pain in them. The general joints at the moment, they are painful.

(Are you pleased or do you regret having the operation)

Oh, I don't regret. I am pleased.

(What is the best thing about the operation?)

Just being able to cough and laugh and sneeze without being wet.

(What is the worst thing about the operation?)

The worst thing. There was no really worst thing. Nothing comes to mind.

(If you had a friend who was going to have this operation done is there anything you would say to her?)

No. There was just a lady I spoke to when I was on the ward who had it done. I spoke to someone the other day whose friend had it done and it was no good. It didn't work.

(If one of your friends came to you and said they were going to have this done, what would you say to her?)

I'd tell her to go for it. Definitely, go for it, have it done.

Case study 12

Preoperative repertory grid

She would like to be able to walk for as long as she wants. Her hopes and expectations are the same for the constructs as active as I want and not embarrassed. Her expectations are slightly less than her hopes for no leakage, able to do what I want, able to walk as long as I want and not being conscious of my bladder control. She does not expect to be as good as before the bladder problems started.

She likes good food and wine, exercise and being with her family and these are enjoyable, good for you, and affect positively. She does not like celebrity big brother, wet weather and other people smoking. Her constructs are not consistently applied to things she likes or does not like and these are less sociable/more sociable, not good for you/good for you, involves interaction/does not involve interaction and natural/artificially manufactured

Situations affected by incontinence

UI causes the most difficulties when walking with family/friends, dancing if out in the evening, running for exercise, times when leakage has occurred and she has been unable to change her clothes and explaining to her children why she has to go to into hospital. Her incontinence is less of a problem to her when sedentary – at work,

when she is able/willing to restrict fluid intake, during her period when she has a pad on anyway, cycling instead of running/walking for exercise and at night. She wears one to three liners per day to absorb leakage.

Preoperative interview summary

As a child, fear was a very potent cause of her wetting herself. There were times at school, even at the age of 10 when a teacher would get angry and she would wet herself. That became less of a problem as she got older and tended to become less anxious about being told off.

She doesn't remember much from 10 to 17. When she was 17 and working in a sweetie shop she remembers wetting herself. She can't remember if it was not getting to the loo in time. She had a similar episode as a student, out with a friend. It was out of the blue and these were isolated occasions.

She first noticed her problem from the stress point of view after her first child was born and she had forgotten to go to the loo just before she'd gone out. She remembers being very aware of the fact that she needed to go to the loo and thinks it just got worse with each child. To begin with it was all around running; it didn't bother her much at other times. She planned her runs so she didn't drink too much fluid for the few hours before she went out. Then after her third child, she began to notice that she was becoming damp at times apart from when she was running and at that stage she started wearing a panty liner all the time. When she was pregnant with her 4th

child she noticed she was wet even going for a walk, which she hoped would get better after the birth but it's just continued.

That is when she went to her GP and asked him to refer her. She was put on detrusitol and advised to get some physio. She did a couple of sessions of physio and it helped a little but then she read about duloxetine and contacted Mr__ (urogynae) and asked about starting that. It was great for the first two weeks because she felt so sick and didn't want to drink anything. Once the nausea settled down it became less effective because she was back to drinking normal quantities. But it probably helped a little. It has got to the point that it is restricting her life in ways and she doesn't want it to so she thought it was worth looking into surgery.

She thinks because she is very active it restricts her activity and if she had a sedentary desk job she may not notice as much. Because her husband and her do activity and walk a lot it does affect that significantly. It affects the way she feels about herself as well. She watches what she does. Friends have asked her to do Ceroc dancing, and she knows she couldn't do that. There are things she would never attempt to do because of it. She does not tell her friends why and does not talk about it. Only in the last 6 months her husband has become aware of how much it affects her. She just tailors her life around it. Once or twice when she has had sex she has been slightly damp. Not a regular thing. It is usually okay but sometimes she is conscious of it and never goes to bed without emptying her bladder completely.

She is thinking about the surgery more now. She was thinking it was just an operation, now she is thinking more, about the short term, family commitments, work etc. She wonders how much she'll be able to do soon after, not the incontinence but 'not ruining whatever work has been done'. Will she be able to drive, walk the children to school, work. That sort of thing. And she is hoping it is going, in the long term, to actually be effective.

She is hoping she won't have to wear liners anymore and able to go for a walk with the family without wondering how damp she is going to be at the end of it. She is wondering whether what Mr___ (urogyn) mentioned about urge incontinence might become an issue.

If he does the repair, she is hoping that will make her feel more comfortable. Not that it's a major problem but it is certainly something she is aware of. It would be nice if her and her husband got more sensation when they have intercourse and that she might be able to keep a tampon in which is a problem. She can but it just tends to fall out sooner than it used to. '*I don't have too many expectations.'*

She then started asking questions about the success rates of TVT and I told her about 80% but that there was a debate about how it was measures and could be as low as 55-60%. She also asked about returning to normal activities, exercise, work etc and I tried to address her points. She asked how urgency can result and we discussed that too.

Urodynamics

Preoperatively she had USI and postoperatively urodynamics were normal. A couple of years previously she had DO and USI on urodynamics. Postoperatively urodynamic studies were normal.

Kings Health Questionnaire

Domain	Score	Score
General Health Perception	0	0
Incontinence Impact	100	0
Role Limitations	33.33	0
Physical Limitations	50	0
Social Limitations	44.44	0
Personal Relationships	55	0
Emotions	55.56	11.11
Sleep / Energy	66.67	16.67
Severity measures	80	13.33

Assessment of subjective success of surgery for stress incontinence

She feels her operation has been completely successful (scoring 10 where O is not successful and 10 is completely successful). She is completely satisfied with the outcome of her operation (scoring 10 where 0 is not satisfied at all and 10 is completely satisfied). She is fairly happy at the moment (scoring 7.7 where 0 is very unhappy and 10 is very happy). She is fairly relaxed at the moment (scoring 1.5 where 0 is very relaxed and 10 is very tense). She rarely leaks now (scoring 9.4 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grids

She is able to run. She is better than she hoped to be for most of her constructs which are bad/good, activity severely restricted/active, feeling negative/feeling positive, no leakage/leakage, not worrying about the bladder/worrying about the bladder. She is nearly as good as before the bladder problems started.

She likes going to see a good film, holidaying with family and friends and a really comfortable pair of shoes. These are relaxing, enjoyable and real situations. She does not like tinned spaghetti, running very late at work and nylon sheets. These are tense, not enjoyable and constant. Other constructs she uses that are inconsistent with the activities are not sociable/sociable and no interaction/interacting with people.

Situations affected by incontinence

Her incontinence causes her the most difficulties at work if held up from visiting loo when necessary. It is less of a problem where she has free access to loo the without time constraints. She does not wear pads or any extra protection.

Postoperative interview summary

The operation seemed to go well. She was possibly initially a little disappointed that he didn't want to do a repair but in retrospect it was probably the correct decision particularly with respect to recovery time and restrictions on activity postoperatively. It meant she got back to normal very quickly. She was out of hospital sooner than she thought she would be with no discomfort. She rested for one week but was keen to start driving as soon as possible and was driving by six days as she was told she could drive if she could stamp her foot. She was back at work at two weeks, which was sooner than she expected or they expected to see her, but it was fine. There weren't any problems going back and then from there she just gradually increased activity and was pleasantly surprised to find that she could walk without leaking. When she started to run she found that was fine as well. There was a continued amount of disbelief that it could have gone as well as it did and there are probably still times when she is thinking it is going to return.

Related to the preoperative interview.

1. Have you been running?

Yep.

If so - Have you planned you fluids before?

Em, no. not, no, I haven't

Have you been to the toilet before?

Yes

2. Are you damp at times other than running?

Apart from the occasional urge

(With dampness?)

Yes on occasions this happens and I am a little bit damp

3. Are you wearing pads all the time?

Not at all

4. Would you be wet going for a walk?

No

5. Do you feel that the bladder is restricting your life?

No

6. Is it restricting your activity?

No

7. Does it affect the walking you do with your husband?

No

8. You said that the bladder affected how you feel about yourself. How do you feel about that now?

More positive

9. Do you feel that you would be able to try something like Ceroc dancing?

Yes.

(Have you tried anything new?)

Running in the evening after work. I would always have avoided that before because of fluid intake before wouldn't have allowed it. And I just remembered, I did go to a

hotel and there was a disco and I danced with the children for a good hour and a half, which I would not have been able to do before.

10. Are there other things you would do now that you would not have attempted before?

(see above)

11. Do you still not talk about the bladder much or have you been talking more since the operation?

Probably don't talk about it much

12. Do you still feel that you tailor your life around the bladder?

No

13. Have you had sex since the operation?

Yes

If so - Was there any dampness or leakage?

No

Were you conscious of the possibility of leakage?

No

14. Could you go to bed now without emptying your bladder?

I never thought to try. I just automatically do.

15. Have you been able to drive?

Yes

16. Have you been able to walk the children to school?

Yes

17. Do you feel that the operation has been effective?

I do

18. Do you still have to wear liners?

No

19. Have you been able to go for a walk with the family without wondering how damp you are going to be at the end of it?

Yep

20. Have you had any problems with urge incontinence?

Minor I would say. It is no different to now it was and I can usually work and I realised I hadn't been to the loo for 6 hours – so it is hardly surprising. There is generally a reason behind it.

21. Did you have a repair?

No

(Are you any more comfortable from the prolapse point of view?)

No. Not particularly uncomfortable. Much more conscious about pelvic floor exercises – so whether that has helped

(So do you feel there has been an improvement?)

Do you get more sensation during intercourse now?

And your husband?

There seems to be a bit more anyway whether the exercises,

(Or maybe you feel more relaxed?)

Possibly

Have you been able to keep a tampon in?

No different to before. Sometimes I do, sometimes I don't.

(Are you pleased or do you regret having the operation?)

Pleased

(What is the best thing about having the operation?)

The freedom it has given me

(What is the worst thing about the operation?)

I suppose having two weeks off work but I would say it is a big problem.

(If a friend told you she was going to have this operation, what would you say to her?)

Encourage her strongly

(Is there anything else we haven't covered?)

Don't think so.

Case study 13

Preoperative repertory grid

She would like to be able to go jogging. She hopes to be the same as before the bladder problems started but does not expect this in relation to her ability to play with her children, exercise and jog. She does expect to be able to be normal sexually; able to cough without leaking, and able to run for the bus as well as before she had bladder problems.

She enjoys shopping, bingo and taking the kids out places. With these activities she is able to take sanitary towels with her, they help her to relax, she can do them with her husband and she does not have to rush home quickly. She does not like taking extra underwear and towels with her, not being able to join in with the kids running and not being able to enjoy sex with her husband. Her constructs are not consistent through the things she does not like. Her bipolar constructs are able/not able to take sanitary towels with her, leave the kids at home/take the kids, with/not with my

husband, feel/do not feel I am failing the kids, helps/does not help me to relax and does/does not have to run home quickly.

Situations affected by incontinence

Her incontinence causes her the most difficulties running, jogging, sex, can't play around with the children, always going to the toilet. She does not give any situation were her incontinence is less of a problem to her. She wears seven to eight sanitary towels a day to save her changing underwear all the time.

Preoperative interview summary

It started ten to fourteen years ago just after her eldest son was born. She developed a cough and started leaking. She went to see her GP and he said there was nothing they could do and it just got worse from there. She went back to her GP two years ago and had tests done and physio. She couldn't go to physio because she had her period. She knows they don't mind but it felt dirty to her. '*I don't like people poking about when I've got me monthly'.* She tried pelvic floor exercises at home and then went to see her doctor again who referred her back to see the consultant.

The bladder is terrible. Normally she can drink lots of drinks during the day. She has had to cut a couple of drinks out. When she has a full bladder and cough it comes out of her. Sometimes she doesn't get to the toilet in time. She has problems sneezing, jumping up and down, running up and down the stairs, things like that. She and her husband had to stop having sex around 15 months ago. '*Everytime we have sex it*

was guaranteed I'd leak and it's embarrassing for him 'cause he thinks he's done wrong.' She can go jogging with her kids any more and she would love to.

She is having surgery because she can't cope with the constant changing of sanitary towels. She is in the shower twice a day now. She feels as though people are moving away from her 'cause she smells. She has also had to start buying vaginal wipes to take with her when she does go out. She decided to go for surgery for her, to get it done and get back on her feet, back to normal activity.

If surgery is anything like the last time she was under '*God help me!' (Laughs).* She is hoping the surgery is going to be a lot better than when she was sterilized because I was really bad then. The morphine didn't agree with her and she just kept being sick and fainted as she came out of the toilet and they had to a fan to calm her down.

After surgery she will be able to think about going out a lot more without having to worry about protection, clean underwear, clean towels, clean trousers and go out with a lighter bag.

Urodynamics

Preoperatively gross USI was demonstrated. The lines fell out so voiding function was not fully examined. She declined to have postoperative urodynamics.

Kings Health Questionnaire

Domain	Preop Score	Postop Score

General Health Perception	50	25
Incontinence Impact	100	0
Role Limitations	83.33	0
Physical Limitations	83.33	0
Social Limitations	11.11	11.11
Personal Relationships	66.66	50
Emotions	100	0
Sleep / Energy	66.67	16.67
Severity measures	86.67	26.67

Assessment of subjective success of surgery for stress incontinence

She feels her operation has been successful (scoring 9.9 where 0 is not successful and 10 is completely successful. She is satisfied with the out come of her operation (scoring 9.8 where 0 is not satisfied at all and 10 is completely satisfied). She feels happy at the moment (scoring 9.5 where 0 is very unhappy and 10 is very happy). She is neither tense not relaxed (scoring 4.7 where 0 is very relaxed and 10 is very tense). She rarely leaks (scoring 9.3 where 0 is leaking all the time and 10 is never leaking).

Postoperative repertory grids

She can run for a bus. She is as good as she hoped to be and better than she expected for most of her constructs can do nothing/able to do things, not able/able to

do any, able/not able to run, pain/no pain and not able/able to do things with the kids. She has scored feeling older now than at any other time.

She likes shopping, playing with the kids and going to bingo. These are relaxing, and she likes them but there are arguments. She does not like going to the cinema, fights and housework. These are not relaxing and the kids can do them on their own. Her other construct that is not consistently scored is can/can not take the kids.

Situations affected by incontinence

Her incontinence caused her the most difficulties as she couldn't run anywhere, no sex, couldn't go out without protection, always needed the toilet, leaked after coughing/sneezing. There were no situations where it was not a problem.

She wears one sanitary towel per day just for days out, because of a bad cough.

Postoperative interview

Her operation went really well, a lot better than she expected. She was sore for about three weeks afterwards. She also was bleeding worse with her period. She could do nothing for about six weeks after the operation and she just started getting back to normal. She has not been able to walk very far. Since the operation her thighs have been really hurting and she is not able to use the right arm a lot.

Related to her preoperative interview.

1. Do you still leak when you are coughing?

It depends on how bad the cough is. If it is only a little cough no, if it is really bad then yes. (Is this an improvement or the same?) Yes a lot of improvement, ‘cause I leaked all the time no matter how much I coughed.

2. Are you still cutting drinks out or can you drink whatever you want?

No. I’m drinking a lot more actually now.

3. When you have a full bladder and cough, does it still come out of you?

No

4. Do you ever not make it to the toilet in time since the operation?

No. I can hold it a lot longer now. I can actually go through the night as well and I can make it to the toilet, which is downstairs and makes it hard.

5. Do you leak with sneezing?

No

6. Do you leak with jumping up and down?

I haven’t tried that one. I ran this morning for the bus and I never leaked at all.

7. Do you leak with running up and down the stairs?

No

8. Have you been able to have sex since the operation?

No. Not yet.

(Any reason?)

‘cause I’m still sore below

9. Have you been able to go jogging with your children?

No, not yet.

(Do you think you will?)

Most probably when it gets warmer we’ll go out, yes, but not till then.

10. Do you still have to constantly change sanitary towels?

No. Once I've taken that one off I don't put one on, unless I've got my monthly. That's the only time I constantly use them.

11. Do you still have to shower twice a day?

If I'm going places like the hospital, yes I do. If not I just have one in the evening. I have a good wash in the morning and a shower in the evening.

12. Do you still feel as though people are moving away from me because you smell?

No

13. Do you still use vaginal wipes and take them with you when you go out?

I still use them. But I don't take them out with me now.

14. Do you feel you are back on your feet now?

Yes

15. Are you back to normal activities?

Not all activities.

(Which ones are back to normal?) I can go out longer times now and not worry about getting back to change or anything like that.

(Which things are not?) Em, running, jumping for the kids and that.

16. You were worried that you would be sick with the morphine like after your sterilisation. Did that happen this time?

I didn't have any morphine. The only pain relief I had was dissolvable paracetamol.

(And you fainted before?)

No, I was fine this time.

17. Have you been able to think about going out a lot more without having to worry about protection, clean underwear, clean towels, and clean trousers and go out with a lighter bag?

Yes. Uh hum. (*Laughs*) A lot lighter bag.

(Are you pleased or do you regret having the operation?)

No. I haven't regretted it at all. I am just grateful I had it done now.

(What is the best thing about the operation?)

Not leaking anymore. I can do what I want without worrying. 'cause the consultant I saw before, she told me there was only a certain percentage rate of it being successful. It could be either too tight or too loose.

(What is the worst thing about the operation?)

Em. Just being sore afterwards, that is all.

(If a friend was going to have this operation what would you say to her?)

Have it done

Case study 14

Preoperative repertory grids

She would like to be able to play with her children without thinking about running and jumping. Her hopes and expectations are the same in relation to thinking about precautions such as space knickers and going home and she hopes and expects to be as good as before the bladder problems started in this respect. Her hopes are slightly better than her expectations for all her other constructs which are having to weigh up doing physical activities against not, worrying about activities with the children, physically comfortable, annoyed, able to do aerobics.

She really enjoys socialising, physical activity and being at home with her family. These are fun, not stressful and she feels better afterwards. She does not like rushing, being messed about or dealing with naughty children. These are stressful, not fun and she doesn't feel better afterwards. With the family and using physical strength are her other constructs.

Situations affected by incontinence

Her incontinence causes her the most difficulties during physical activity e.g. aerobics, jogging, playing with kids, minding kids (keeping them safe- away from road etc), rushing (running for bus) and with accidents – stumbling or tripping. Her incontinence is less of a problem to her working, walking, relaxing, driving and doing housework. She sometimes wears an ultra always pad in case of leaks.

Preoperative interview summary

She was fine until she had her first child. She had quite a long labour, an induction, an epidural and was pushing for about two hours and ended up with forceps. He was quite a big baby and was overdue and had a hard head which all really conspired she supposes. She did do pelvic exercises after but she thinks she was doing them a bit wrong.

She first noticed the problem when she was walking the dog. If he pulled or jerked her on the lead she'd leak. She was expecting that it would get better but when she had healed up that didn't improve. If she coughed, sneezed or ran.

Then she got pregnant again and had a child at home. There were no problems whatsoever. She did her exercises again. The problem got worse so she saw her doctor and he referred her for physiotherapy. When her second child was one she did physio for six months and that made things a bit better. She could brace herself better she helped her with her bladder, trying to go to the toilet less and gave her standard bladder advice. She did all she could but knew she wanted another child. It was good she taught her the pelvic floor exercises properly.

She changed all her physical activities to avoid leaking. She stopped aerobics; Doesn't run unless she has to. She is better with the dog and braces herself in case he jerks. If she coughs she stops and braces herself.

She did used to carry spare knickers and wear more pads but decided that was a bit defeatist so she tends not to unless she has a meeting or something else she can't get home from. She thinks it is sad because playing tag and things like that is fun and a bit basic really. She went back to her GP and he referred her to urodynamics first and the urodynamics referred her to physiotherapy again. She did biofeedback for five months, which was really useful, and it got it a bit better but still not remotely where she wants to be.

She thought about the drugs but the side effects seemed a bit off putting so she thought she'd have the TVT and if it doesn't work think again. So if it works enough to let her do some things then that'll just have to do.

After the operation she hopes that she'll be better. She is a bit of a cynic and worries that it won't be better and her worst fear is it will actually be worse but she is trying to be optimistic. '*I might be one of the ninety percent mightened I?'*

To be able to do aerobics would be fantastic and going for a jog and just having a whale of a time with the kids and not worrying and not having to worry when she's got a cough. (*Laughs*). She hopes to be more adventurous in general and more spontaneous. She did find the physio useful and the fact that she had been doing the exercise incorrectly. It was controlling that she could control that and that she had been doing them wrong. She was moving forward and did find it useful to be doing something about it rather than just accepting it.

Urodynamics

Preoperatively moderate USI was demonstrated. She declined postoperative urodynamics.

Kings Health Questionnaire

Domain	Preop Score	Postop Score
General Health Perception	25	25
Incontinence Impact	100	66.67

Role Limitations	33.33	16.67
Physical Limitations	66.67	0
Social Limitations	44.44	11.11
Personal Relationships	0	0
Emotions	33.33	22.22
Sleep / Energy	33.33	50
Severity measures	33.33	6.67

Assessment of subjective success of surgery for stress incontinence

She feels her operation has been successful (scoring 9.9 where 0 in not successful and 10 is completely successful). She is somewhat satisfied with the out come of her operation (scoring 7.4 where 0 is not satisfied at all and 10 is completely satisfied). She feels moderately happy at the moment (scoring 7.35 where 0 is very unhappy and 10 is very happy). She feels relaxed at the moment (scoring 3.45 where 0 is very relaxed and 10 is very tense). She never leaks (scoring 10 where 0 is leaking all the time and 10 is never leaking.

Postoperative repertory grids

She can run which she could not do before. She is how she hoped to be and better than she expected to be in relation to ability to run, ability to be spontaneous, having no leakage and to push herself and the same as before the bladder problems started.

She is how she expected but not as good as she hoped or before the bladder problems started in relation to worrying about leaking and feeling stressed.

She enjoys playing with her children, working and socialising and these are busy, fun and interesting. She does not like waiting, doing the garden and cleaning and these are less brain work, not fun and boring. Her other construct vary across all elements and these are less physical/more physical and not stressful/stressful.

Situations affected by incontinence

Her incontinence caused her the most difficulties playing with kids, walking dog (if he jerked his lead), running for bus, when she had a cough and sneezing unexpectedly. Her UI was incontinence is less of a problem to her working, watching telly/relaxing, socialising, driving and cleaning. She does not wear pads or any extra protection.

Postoperative interview summary

Her operation was more complicated than she thought and although she had no pain she had problems having a wee so she had to be catheterised and come in with a bag for a week which was very difficult with the children. She thinks she had a bladder infection at the time and had antibiotics. She came back in the next week and apparently wasn't emptying her bladder properly but was weeing. The nurse taught her to self catheterise and they discovered that 100mls of what the bladder scan was picking up must be some kind of swelling as on catheterisation she was empty and she scanned me and there was still 100mls.

She was a bit cross about her nursing care because she wasn't told not to drink much the night before her trial without catheter and they didn't give her an anti-inflammatory. They didn't count a wee less than 150mls, which she found very stressful and was scared to go when she needed in case it wasn't enough. When she came back in she was at the other side of the ward where they didn't seem to have this rule about 150mls. She still had problems emptying properly and the nurses would have catheterised her otherwise without a need.

Then she went home self-catheterising night and morning for about five days and the amount was getting was down to 10mls, 20mls and zero. So she spoke to the nurse who said to leave it a few days and do one, like a spot check and that was under 40mls so she stopped. It was still different weeing especially at night it seems to be slightly harder to empty her bladder, it is not a big whoosh. She sometimes has to go back to the toilet in the morning and have a big wee then.

She still thinks she has a bladder infection. She came in and thought she had a prolapse, but wonders if some of the sensation was a bladder infection and coincided with her seeing something, a bit more flesh than she had expected.
Every week to 10 days she starts to get symptoms of an infection. But drinking the bicarb and fluid seems to stave it off. She doesn't know what triggers it. She thinks she had cystitis once before in her life before this. Her wee smells chemical. Not a foul smell but a chemical smell she hasn't had before. She hasn't noticed it so much recently. She feels she is having to empty her bladder more often than she had to but thinks that might be the infection if there is one and she is deliberately doing that.

She is pleased that the leaking seems to have stopped but she is anxious about the complications. She did catheterise herself yesterday to see if it was because she wasn't emptying properly but it was only 40mls so she doesn't think it is necessarily a big build up or anything.

Related to her pre-operative interview

1. Do you have bladder problems when you are walking the dog since the operation?

Eh, no.

2. Do you leak if you cough?

Em, I haven't coughed that much to be honest, I don't know.

3. Do you leak if you sneeze?

I haven't yet. You are so used to crossing your legs. I am going to have to consciously not cross my legs to see if it is okay

4. Do you leak if you run?

No

5. Have you tried aerobics since the operation?

I haven't, no.

6. Do you still brace yourself when walking the dog in case he jerks?

Em, yeh, I probably do. Going to be a hard habit not to

7. Do you carry spare knickers with you?

No

8. Do you carry spare pads with you?

Eh, not, no.

9. Have you been able to play tag with your children?

Yes. Yip.

10. Do you feel as though the TVT has worked?

Em. In that it stopped me leaking, yes.

11. Do you think you are better since the operation?

I don't know what you mean by better. There are pros and cons really.

(I explained that she will have used these words and found the passage in her original interview)

I am a bit of a pessimist!

12. Do you think you are worse since the operation?

It is not worse in terms of the leaking but I am very anxious about the bladder infection.

13. Have you been able to go for a jog?

Yes

14. Have you been able to have a whale of a time with the kids?

Yeh

15. Do you still worry when you have a cough?

Well, I haven't had a cough yet. I am sure I will worry but

16. Do you feel that you are more adventurous in general?

Eh, yeh

17. Do you feel that you are more spontaneous?

Yep

(Are you pleased or do you regret having the operation?)

I am pleased with the leakage and anxious about the complication. (Overall?) I don't know yet (too early to tell?) yes

(What is the best thing about the operation?)

That I can be spontaneous

(And the worst thing?)

These, whatever it is, bladder infections, going on

If you had a friend who was going to have this done what would you say to her?)

laughs again it is too early to say I think. I think I am too biased (you'd probably just be quiet?)

I would be quiet, yep.

APPENDIX XIII

PRESENTATIONS AND PUBLICATIONS

Robb K, Toozs-Hobson P. Striving towards tailored urogynaecology management plans. Int Urogynaecol J 2007; 18:709-711.

Striving towards tailored urogynaecology management plans. British Society of Urogynaecologists Annual Research Meeting; 2006.

Robb K, Toozs-Hobson P, Hicks C. Development of a treatment planning tool for urinary incontinence. Use of the Repertory grid technique. International Continence Society. 2006.

Robb K. Is there a place for cognitive behavioural therapy in urogynaecology? International Urogynaecological Association. 2006.

Robb K. Is dry happy? International Continence Society. 2005.

Robb K. Treatment Planning in Urogynaecology. Can we do better? UK Continence Society. 2007.

Robb K. Psychological aspects of urinary incontinence. Midland Urogynae Society. 2005.

Psychological Aspects of Female Urinary Incontinence. Midland Urogynae Society; 2005.

Loane K, Toozs-Hobson P, Hicks C. Women's Experiences of Stress Incontinence Surgery. International Continence Society 2009.

Robb K. Psychological Aspects of Female Urinary Incontinence. Ulster Gynae Urology Society. 2006.

Toozs-Hobson P, Loane K. The psychology of incontinence. Why successful treatments fail. Margie Polden Memorial lecture. Association of Chartered Physiotherapists in Women's Health 2008;(102).

Reference List

(1) Robb K, Toozs-Hobson P. Striving towards tailored urogynaecology management plans. Int Urogynaecol J 2007; 18:709-711.

(2) Striving towards tailored urogynaecology management plans. British Society of Urogynaecologists Annual Research Meeting; 06; 2006.

(3) Robb K, Toozs-Hobson P, Hicks C. Development of a treatment planning tool for urinary incontinence. Use of the Repertory grid technique. International Continence Society. 2006. 2006.
Ref Type: Unpublished Work

(4) Robb K. Is there a place for cognitive behavioural therapy in urogynaecology? International Urogynaecological Association. 2006. 2006.
Ref Type: Unpublished Work

(5) Robb K. Is dry happy? International Continence Society. 2005. 2005.
Ref Type: Unpublished Work

(6) Robb K. Treatment Planning in Urogynaecology. Can we do better? UK Continence Society. 2007. 2007.
Ref Type: Unpublished Work

(7) Robb K. Psychological aspects of urinary incontinence. Midland Urogynae Society. 2005. 2005.
Ref Type: Unpublished Work

(8) Psychological Aspects of Female Urinary Incontinence. Midland Urogynae Society; 05; 2005.

(9) Loane K, Toozs-Hobson P, Hicks C. Women's Experiences of Stress Incontinence Surgery. International Continence Society 2009. 2009. 2009.
Ref Type: Unpublished Work

(10) Hafner RJ, Stanton SL, Guy J. A psychiatric study of women with urgency and urgency incontinence. Br J Urol 1977; 49(3):211-214.

(11) Macaulay AJ, Stern RS, Holmes DM, Stanton SL. Micturition and the mind: psychological factors in the aetiology and treatment of urinary symptoms in women. Br Med J (Clin Res Ed) 1987; 294(6571):540-543.

(12) Department of Health. Choice Matters 2007-2008. Putting patients in control. 2008.
Ref Type: Report

(13) National Centre for Health Outcomes Development. National Centre for Health Outcomes Development. http://www nchod nhs uk/ [2010 [cited 10 A.D. Jan. 22]; Available from: URL:http://www.nchod.nhs.uk/

(14) Elkadry EA, Kenton KS, FitzGerald MP, Shott S, Brubaker L. Patient-selected goals: a new perspective on surgical outcome. Am J Obstet Gynecol 2003; 189(6):1551-1557.

(15) Hullfish KL, Bovbjerg VE, Gibson J, Steers WD. Patient-centered goals for pelvic floor dysfunction surgery: what is success, and is it achieved? Am J Obstet Gynecol 2002; 187(1):88-92.

(16) FitzGerald MP, Kenton K, Shott S, Brubaker L. Responsiveness of quality of life measurements to change after reconstructive pelvic surgery. Am J Obstet Gynecol 2001; 185(1):20-24.

(17) Bidmead J, Cardozo L, McLellan A, Khullar V, Kelleher C. A comparison of the objective and subjective outcomes of colposuspension for stress incontinence in women. BJOG 2001; 108(4):408-413.

(18) Black NA, Bowling A, Griffiths JM, Pope C, Abel PD. Impact of surgery for stress incontinence on the social lives of women. Br J Obstet Gynaecol 1998; 105(6):605-612.

(19) Garley A, Unwin J. A case series to pilot cognitive behaviour therapy for women with urinary incontinence. Br J Health Psychol 2006; 11(Pt 3):373-386.

(20) Freeman RM, Baxby K. Hypnotherapy for incontinence caused by the unstable detrusor. Br Med J (Clin Res Ed) 1982; 284(6332):1831-1834.

(21) Yip SK, Chan A, Pang S, Leung P, Tang C, Shek D et al. The impact of urodynamic stress incontinence and detrusor overactivity on marital relationship and sexual function. Am J Obstet Gynecol 2003; 188(5):1244-1248.

(22) Tyrer P, Mitchard S, Methuen C, Ranger M. Treatment rejecting and treatment seeking personality disorders: Type R and Type S. J Personal Disord 2003; 17(3):263-268.

(23) Abrams P, Cardozo L, Fall M, Griffiths D, Rosier P, Ulmsten U et al. The standardisation of terminology of lower urinary tract function: report from the Standardisation Sub-committee of the International Continence Society. Neurourol Urodyn 2002; 21(2):167-178.

(24) Hunskaar S, Lose G, Sykes D, Voss S. The prevalence of urinary incontinence in women in four European countries. BJU Int 2004; 93(3):324-330.

(25) Wilkinson K. Pakistani women's perceptions and experiences of incontinence. Nurs Stand 2001; 16(5):33-39.

(26) Dowd TT. Discovering older women's experience of urinary incontinence. Res Nurs Health 1991; 14(3):179-186.

(27) Ashworth PD, Hagan MT. The meaning of incontinence: a qualitative study of non-geriatric urinary incontinence sufferers. J Adv Nurs 1993; 18(9):1415-1423.

(28) Haylen BT, de Ridder D, Freeman RM, Swift SE, Berghmans BLJ, Monga A et al. An International Urogynaecological Association (IUGA) / International Continence Society (ICS) joint report on the terminology for pelvic floor dysfunction. 7-12-0009.
Ref Type: Report

(29) Department of Health. Good Practice in continence services.
Ref Type: Generic

(30) Donaldson MM, Thompson JR, Matthews RJ, Dallosso HM, McGrother CW. The natural history of overactive bladder and stress urinary incontinence in older women in the community: a 3-year prospective cohort study. Neurourol Urodyn 2006; 25(7):709-716.

(31) Fultz NH, Burgio K, Diokno AC, Kinchen KS, Obenchain R, Bump RC. Burden of stress urinary incontinence for community-dwelling women. Am J Obstet Gynecol 2003; 189(5):1275-1282.

(32) Lee PS, Reid DW, Saltmarche A, Linton L. Measuring the psychosocial impact of urinary incontinence: the York Incontinence Perceptions Scale (YIPS). J Am Geriatr Soc 1995; 43(11):1275-1278.

(33) Incontinence Foundation. Making the case for investment in an integrated health service. 26-4-2005.
Ref Type: Internet Communication

(34) Birnbaum H, Leong S, Kabra A. Lifetime medical costs for women: cardiovascular disease, diabetes, and stress urinary incontinence. Womens Health Issues 2003; 13(6):204-213.

(35) Scottish Intercollegiate Guidelines Network. Management of urinary incontinence in primary care. A national Clinical Guideline. 2004.
Ref Type: Report

(36) Bump RC, Norton PA. Epidemiology and natural history of pelvic floor dysfunction. Obstet Gynecol Clin North Am 1998; 25(4):723-746.

(37) Robb K, Toozs-Hobson P. Nulliparous Women. In: Cardozo L, Staskin D, editors. Textboob of Female Urology and Urogynaecology. 2 ed. Informa Healthcare; 2006. 673-680.

(38) National Institute for Health and Clinical Excellence. Urinary Incontinence. The management of urinary incontinence in women. 2006.
Ref Type: Generic

(39) Laycock J. Patient Assessment. In: Haslam J, Laycock J, editors. Therapeutic Management of Incontinence and Pelvic Pain. 2nd ed. Springer; 2008. 57-66.

(40) Samuelsson E, Victor A, Svardsudd K. Determinants of urinary incontinence in a population of young and middle-aged women. Acta Obstet Gynecol Scand 2000; 79(3):208-215.

(41) Thakar R, Stanton S. Regular review: management of urinary incontinence in women. BMJ 2000; 321(7272):1326-1331.

(42) Bump RC, Sugerman HJ, Fantl JA, McClish DK. Obesity and lower urinary tract function in women: effect of surgically induced weight loss. Am J Obstet Gynecol 1992; 167(2):392-397.

(43) Steele AC, Kohli N, Mallipeddi P, Karram M. Pharmacologic causes of female incontinence. Int Urogynecol J Pelvic Floor Dysfunct 1999; 10(2):106-110.

(44) Lamb SE, Pepper J, Lall R, Jorstad-Stein EC, Clark MD, Hill L et al. Group treatments for sensitive health care problems: a randomised controlled trial of group versus individual physiotherapy sessions for female urinary incontinence. BMC Womens Health 2009; 9:26.

(45) Tadic SD, Zdaniuk B, Griffiths D, Rosenberg L, Schafer W, Resnick NM. Effect of biofeedback on psychological burden and symptoms in older women with urge urinary incontinence. J Am Geriatr Soc 2007; 55(12):2010-2015.

(46) Andersson KE, Pehrson R. CNS involvement in overactive bladder: pathophysiology and opportunities for pharmacological intervention. Drugs 2003; 63(23):2595-2611.

(47) Merck. Oxybutynin. Drug information provided by Lexi-Comp. www merck com [2010 Available from: URL:http://www.merck.com/mmpe/lexicomp/oxybutynin.html#N15652D

(48) Dmochowski RR, Miklos JR, Norton PA, Zinner NR, Yalcin I, Bump RC. Duloxetine versus placebo for the treatment of North American women with stress urinary incontinence. J Urol 2003; 170(4 Pt 1):1259-1263.

(49) Millard RJ, Moore K, Rencken R, Yalcin I, Bump RC. Duloxetine vs placebo in the treatment of stress urinary incontinence: a four-continent randomized clinical trial. BJU Int 2004; 93(3):311-318.

(50) van KP, Abrams P, Lange R, Slack M, Wyndaele JJ, Yalcin I et al. Duloxetine versus placebo in the treatment of European and Canadian women with stress urinary incontinence. BJOG 2004; 111(3):249-257.

(51) Thor KB, Katofiasc MA. Effects of duloxetine, a combined serotonin and norepinephrine reuptake inhibitor, on central neural control of lower urinary tract function in the chloralose-anesthetized female cat. J Pharmacol Exp Ther 1995; 274(2):1014-1024.

(52) Hunsballe JM, Djurhuus JC. Clinical options for imipramine in the management of urinary incontinence. Urol Res 2001; 29(2):118-125.

(53) Pacher P, Kecskemeti V. Cardiovascular side effects of new antidepressants and antipsychotics: new drugs, old concerns? Curr Pharm Des 2004; 10(20):2463-2475.

(54) Sullivan J, Abrams P. Pharmacological management of incontinence. Eur Urol 1999; 36 Suppl 1:89-95.

(55) Ward K, Hilton P. Prospective multicentre randomised trial of tension-free vaginal tape and colposuspension as primary treatment for stress incontinence. BMJ 2002; 325(7355):67.

(56) Nilsson CG. Latest advances in TVT tension-free support for urinary incontinence. Surg Technol Int 2004; 12:171-176.

(57) Richter HE, Norman AM, Burgio KL, Goode PS, Wright KC, Benton J et al. Tension-free vaginal tape: a prospective subjective and objective outcome analysis. Int Urogynecol J Pelvic Floor Dysfunct 2005; 16(2):109-113.

(58) de LJ. Novel surgical technique for the treatment of female stress urinary incontinence: transobturator vaginal tape inside-out. Eur Urol 2003; 44(6):724-730.

(59) Moore RD, Mitchell GK, Miklos JR. Single-Center Retrospective Study of the Technique, Safety, and 12-Month Efficacy of the MiniArc Single-Incision Sling: A New Minimally Invasive Procedure for Treatment of Female SUI. Surg Technol Int 2009; 18:175-181.

(60) Bunyaratavej P, La-ornual S, Kongkanand A, Prasopsanti K, Vajarapongse R. Ten years' experience with enterocystoplasty. J Med Assoc Thai 1993; 76(6):327-333.

(61) Mast P, Hoebeke P, Wyndaele JJ, Oosterlinck W, Everaert K. Experience with augmentation cystoplasty. A review. Paraplegia 1995; 33(10):560-564.

(62) Mohanty NK, Nayak RL, Alam M, Arora RP. Role of botulinum toxin-A in management of refractory idiopathic detrusor overactive bladder: Single center experience. Indian J Urol 2008; 24(2):182-185.

(63) Cohen BL, Barboglio P, Rodriguez D, Gousse AE. Preliminary results of a dose-finding study for botulinum toxin-A in patients with idiopathic overactive bladder: 100 versus 150 units. Neurourol Urodyn 2009; 28(3):205-208.

(64) White WM, Pickens RB, Doggweiler R, Klein FA. Short-term efficacy of botulinum toxin a for refractory overactive bladder in the elderly population. J Urol 2008; 180(6):2522-2526.

(65) Macdiarmid SA, Peters KM, Shobeiri SA, Wooldridge LS, Rovner ES, Leong FC et al. Long-Term Durability of Percutaneous Tibial Nerve Stimulation for the Treatment of Overactive Bladder. J Urol 2009.

(66) Peters KM, Macdiarmid SA, Wooldridge LS, Leong FC, Shobeiri SA, Rovner ES et al. Randomized trial of percutaneous tibial nerve stimulation versus extended-release tolterodine: results from the overactive bladder innovative therapy trial. J Urol 2009; 182(3):1055-1061.

(67) Burgio KL, Locher JL, Roth DL, Goode PS. Psychological improvements associated with behavioral and drug treatment of urge incontinence in older women. J Gerontol B Psychol Sci Soc Sci 2001; 56(1):46-51.

(68) Campbell JD, Gries KS, Watanabe JH, Ravelo A, Dmochowski RR, Sullivan SD. Treatment success for overactive bladder with urinary urge incontinence refractory to oral antimuscarinics: a review of published evidence. BMC Urol 2009; 9:18.

(69) Ghoniem GM, Van Leeuwen JS, Elser DM, Freeman RM, Zhao YD, Yalcin I et al. A randomized controlled trial of duloxetine alone, pelvic floor muscle training alone, combined treatment and no active treatment in women with stress urinary incontinence. J Urol 2005; 173(5):1647-1653.

(70) Latthe PM, Foon R, Khan K. Nonsurgical treatment of stress urinary incontinence (SUI): grading of evidence in systematic reviews. BJOG 2008; 115(4):435-444.

(71) Moehrer B, Hextall A, Jackson S. Oestrogens for urinary incontinence in women. Cochrane Database Syst Rev 2003;(2):CD001405.

(72) McCully KS, Jackson S. Hormone replacement therapy and the bladder. J Br Menopause Soc 2004; 10(1):30-32.

(73) Hendrix SL, Cochrane BB, Nygaard IE, Handa VL, Barnabei VM, Iglesia C et al. Effects of estrogen with and without progestin on urinary incontinence. JAMA 2005; 293(8):935-948.

(74) Sand PK, Morrow JD, Bavendam T, Creanga DL, Nitti VW. Efficacy and tolerability of fesoterodine in women with overactive bladder. Int Urogynecol J Pelvic Floor Dysfunct 2009; 20(7):827-835.

(75) Chung DE, Te AE. Tolterodine extended-release for overactive bladder. Expert Opin Pharmacother 2009; 10(13):2181-2194.

(76) Andersson KE, Chapple CR, Cardozo L, Cruz F, Hashim H, Michel MC et al. Pharmacological treatment of overactive bladder: report from the International Consultation on Incontinence. Curr Opin Urol 2009; 19(4):380-394.

(77) Wong C, Duggan P. Solifenacin for overactive bladder in women unsuccessfully treated with immediate release oxybutynin: a pilot study. J Obstet Gynaecol 2009; 29(1):31-34.

(78) Robinson D, Anders K. Outcome measures in urogynaecology; the clinicians' perspective. Int Urogynecol J Pelvic Floor Dysfunct 2007; 18(3):273-279.

(79) Tannenbaum C, Brouillette J, Corcos J. Rating improvements in urinary incontinence: do patients and their physicians agree? Age Ageing 2008; 37(4):379-383.

(80) Kelleher CJ, Pleil AM, Reese PR, Burgess SM, Brodish PH. How much is enough and who says so? BJOG 2004; 111(6):605-612.

(81) Ternent L, Vale L, Buckley B, Glazener C. Measuring outcomes of importance to women with stress urinary incontinence. BJOG 2009; 116(5):719-725.

(82) Lloyd A. The extent of patients' understanding of the risk of treatments. Qual Health Care 2001; 10:14-18.

(83) Langford CF, Elmissiry MM, Ghoniem GM. Do women have realistic expectations of treatment for stress urinary incontinence? Neurourol Urodyn 2008; 27(6):480-484.

(84) Frewer LJ, Salter B, Lambert N. Understanding patients' preferences for treatment: the need for innovative methodologies. Qual Health Care 2001; 10 Suppl 1:i50-i54.

(85) Montgomery AA, Fahey T. How do patients' treatment preferences compare with those of clinicians? Qual Health Care 2001; 10 Suppl 1:i39-i43.

(86) Roe B. Effective and ineffective management of incontinence: issues around illness trajectory and health care. Qual Health Res 2000; 10(5):677-690.

(87) Milne J. The impact of information on health behaviors of older adults with urinary incontinence. Clin Nurs Res 2000; 9(2):161-176.

(88) Majumdar A, Hassan I, Saleh S, Toozs-Hobson P. Inpatient bladder retraining: is it beneficial on its own? Int Urogynecol J Pelvic Floor Dysfunct 2010; 21(6):657-663.

(89) Brown B, Crawford P, Hichs C. Evidence-Based Research Dilemmas and Debates in Health Care. first ed. Open University Press; 2003.

(90) Blaxter L, Hughes C, Tight M. How To Research. 2nd ed. Open University Press; 2002.

(91) Gould D, Kelly D, Goldstone L, Gammon J. Examining the validity of pressure ulcer risk assessment scales: developing and using illustrated patient simulations to collect the data. J Clin Nurs 2001; 10(5):697-706.

(92) Myles PS, Troedel S, Boquest M, Reeves M. The pain visual analog scale: is it linear or nonlinear? Anesth Analg 1999; 89(6):1517-1520.

(93) Elkadry EA, Kenton KS, FitzGerald MP, Shott S, Brubaker L. Patient-selected goals: a new perspective on surgical outcome. Am J Obstet Gynecol 2003; 189(6):1551-1557.

(94) Attride-Stirling J. Thematic networks: an analytic tool for qualitative research. J Qualitative Research 2001; 1(3):385-405.

(95) Berglund AL, Eisemann M, Lalos A, Lalos O. Social adjustment and spouse relationships among women with stress incontinence before and after surgical treatment. Soc Sci Med 1996; 42(11):1537-1544.

(96) Niven N. Health psychology for health professionals. Churchill Livingstone; 1986.

(97) Parahoo K. Nursing Research. 1st ed. Suffolk: Macmillan; 1997.

(98) Hicks C. Undertaking systematic reviews. In: McCubbin, editor. Research methods for clinical therapists. 5th edition ed. Churchill Livingstone; 2009. 327-335.

(99) The Royal College of Obstetricians and Gynaecologists. The management of post hysterectomy vaginal vault prolapse. 2007. Green Top Guideline. Ref Type: Report

(100) Paley J, Lilford R. Qualitative methods: an alternative view. BMJ 2011; 342:d424.

(101) Stewart D. Focus groups: theory and practice. 2nd ed. Sage Publications; 2007.

(102) Kitzinger J. Qualitative research. Introducing focus groups. BMJ 1995; 311(7000):299-302.

(103) Morgan DL. Focus groups. Annual Review of Sociology 1996; 22:129-152.

(104) Kelly G. **The Psychology of Personal Constructs**. Routledge; 1955.

(105) Bannister D, Fransella F. **Inquiring Man: The Psychology of Personal Constructs** . London: Routledge; 1986.

(106) Caine TM, Smail DJ. Personal relevance and the choice of constructs for the repertory grid technique. Br J Psychiatry 1967; 113(498):517-520.

(107) Bannister D. The rationale and clinical relevance of repertory grid technique. Br J Psychiatry 1965; 111(479):977-982.

(108) Slater P. The use of the repertory grid technique in the individual case. Br J Psychiatry 1965; 111(479):965-975.

(109) Fransella F, Adams B. An illustration of the use of repertory grid technique in a clinical setting. Br J Soc Clin Psychol 1966; 5(1):51-62.

(110) Grice JW. Idiogrid: software for the management and analysis of repertory grids. Behav Res Methods Instrum Comput 2002; 34(3):338-341.

(111) Large RG, James FR. Personalized evaluation of self-hypnosis as a treatment of chronic pain: a repertory grid analysis. Pain 1988; 35(2):155-169.

(112) Leach C. GRAN: a computer program for the cluster analysis of a repertory grid. Br J Clin Psychol 1988; 27 (Pt 2):173-174.

(113) Rowe G, Lambert N, Bowling A, Ebrahim S, Wakeling I, Thomson R. Assessing patients' preferences for treatments for angina using a modified repertory grid method. Soc Sci Med 2005; 60(11):2585-2595.

(114) Morrison LM, Eadie AS, McAlister A, Glen ES, Taylor J, Rowan D. Personality testing in 226 patients with urinary incontinence. Br J Urol 1986; 58(4):387-389.

(115) Berglund AL, Eisemann M, Lalos A, Lalos O. Predictive factors of the outcome of primary surgical treatment of stress incontinence in women. Scand J Urol Nephrol 1997; 31(1):49-55.

(116) Clayton J, Smith K, Qureshi H, Ferguson B. Collecting patients' views and perceptions of continence services: the development of research instruments. J Adv Nurs 1998; 28(2):353-361.

(117) Gallagher M, Pierce L. Caregivers' and Care Recipients' Perceptions of Dealing with Urinary Incontinence. Rehabil Nurs 2002; 27(1):25-31.

(118) Horrocks S, Somerset M, Stoddart H, Peters TJ. What prevents older people from seeking treatment for urinary incontinence? A qualitative exploration of barriers to the use of community continence services. Fam Pract 2004; 21(6):689-696.

(119) Hicks C. Research Methods for Clinical Therapists. fifth ed. Churchill Livingstone Elsevier; 2009.

(120) Macaulay AJ, Stern RS, Stanton SL. Psychological aspects of 211 female patients attending a urodynamic unit. J Psychosom Res 1991; 35(1):1-10.

(121) Kelleher CJ, Cardozo LD, Khullar V, Salvatore S. A new questionnaire to assess the quality of life of urinary incontinent women. Br J Obstet Gynaecol 1997; 104(12):1374-1379.

(122) Kelleher CJ, Reese PR, Pleil AM, Okano GJ. Health-related quality of life of patients receiving extended-release tolterodine for overactive bladder. Am J Manag Care 2002; 8(19 Suppl):S608-S615.

(123) Das AK, Carlson AM, Hull M. Improvement in depression and health-related quality of life after sacral nerve stimulation therapy for treatment of voiding dysfunction. Urology 2004; 64(1):62-68.

(124) Wee CC, Davis RB, Hamel MB. Comparing the SF-12 and SF-36 health status questionnaires in patients with and without obesity. Health Qual Life Outcomes 2008; 6:11.

(125) Freeman RM, McPherson FM, Baxby K. Psychological features of women with idiopathic detrusor instability. Urol Int 1985; 40(5):257-259.

(126) Morrison L M. Psychiatric Aspects of Female Incontinence. Int Urogynaecol J 1991; 2:69-72.

(127) Norton KR, Bhat AV, Stanton SL. Psychiatric aspects of urinary incontinence in women attending an outpatient urodynamic clinic. BMJ 1990; 301(6746):271-272.

(128) Ferrie BG, Smith JS, Logan D, Lyle R, Paterson PJ. Experience with bladder training in 65 patients. Br J Urol 1984; 56(5):482-484.

(129) Kent LK, Shapiro PA. Depression and related psychological factors in heart disease. Harv Rev Psychiatry 2009; 17(6):377-388.

(130) van den Broek KC, Nyklicek I, Denollet J. Selection Bias in a Study of Implantable Defibrillator Patients: The Role of Type D Personality. Int J Behav Med 2010.

(131) Boeree CG. Hans Eysenck and other Temperament Theorists. internet [2006 Available from: URL:http://webspace.ship.edu/cgboer/eysenck.html

(132) Kazlev MA. The Four Hunours. internet [2004 Available from: URL:http://www.kheper.net/topics/typology/four_humours.html

(133) Boeree CG. Personality Theories. 2008.
Ref Type: Internet Communication

(134) Bannister D. Personal construct psychotherapy. Br J Hosp Med 1983; 30(1):72-74.

(135) Tuite DR, Luiten JW. 16PF research into addiction: meta-analysis and extension. Int J Addict 1986; 21(3):287-323.

(136) Yang CK, Choe BM, Baity M, Lee JH, Cho JS. SCL-90-R and 16PF profiles of senior high school students with excessive internet use. Can J Psychiatry 2005; 50(7):407-414.

(137) McCrae RR, John OP. An introduction to the five-factor model and its applications. J Pers 1992; 60(2):175-215.

(138) Rammstedt B, Goldberg LR, Borg I. The measurement equivalence of Big Five factor markers for persons with different levels of education. J Res Pers 2010; 44(4):53-61.

(139) Claxton-Oldfield S, Banzen Y. Personality Characteristics of Hospice Palliative Care Volunteers: The "Big Five" and Empathy. Am J Hosp Palliat Care 2010.

(140) Laurin R. The influence of the "big five" factors on the demands-abilities fit in soccer academies. Percept Mot Skills 2009; 109(1):239-250.

(141) Mitchell JR, Baker MC. Religious commitment and the construal of sources of help for emotional problems. Br J Med Psychol 2000; 73 (Pt 3):289-301.

(142) Yang SC, Chen SF. The study of personal constructs of death and fear of death among Taiwanese adolescents. Death Stud 2009; 33(10):913-940.

(143) Izard CE. Emotion theory and research: highlights, unanswered questions, and emerging issues. Annu Rev Psychol 2009; 60:1-25.

(144) Walker BM, Winter DA. The elaboration of personal construct psychology. Annu Rev Psychol 2007; 58:453-477.

(145) Winter DA. Repertory grid technique as a psychotherapy research measure. Psychotherapy Research 2003; 13:25-42.

(146) Birtchnell J, Evans C, Kennard J. The total score of the Crown-Crisp Experiential Index: a useful and valid measure of psychoneurotic pathology. Br J Med Psychol 1988; 61 (Pt 3):255-266.

(147) Zhao H, Seibert SE. The big five personality dimensions and entrepreneurial status: a meta-analytical review. J Appl Psychol 2006; 91(2):259-271.

(148) Sheehan MJ. A personal construct study of depression. Br J Med Psychol 1985; 58 (Pt 2):119-128.

(149) Weber C, Bronner E, Thier P, Schoeneich F, Walter O, Klapp BF et al. Body experience and mental representation of body image in patients with haematological malignancies and cancer as assessed with the Body Grid. Br J Med Psychol 2001; 74(4):507-521.

(150) Ellis JM. Nursing care of older people: a personal construct theory perspective. J Adv Nurs 1999; 29(1):160-168.

(151) McEachan RR, Lawton RJ, Conner M. Classifying health-related behaviours: Exploring similarities and differences amongst behaviours. Br J Health Psychol 2010; 15(2):347-366.

(152) Vogt F, Ashworth M, Hall S, Sniehotta FF, Marteau TM. What underlies the perception that a medical intervention is effective? An exploratory study among smokers. Nicotine Tob Res 2010.

(153) Vogt F, Armstrong D, Marteau TM. General practitioners' perceptions of the effectiveness of medical interventions: an exploration of underlying constructs. Implement Sci 2010; 5(1):17.

(154) Roland KP, Jenkins ME, Johnson AM. An exploration of the burden experienced by spousal caregivers of individuals with Parkinson's disease. Mov Disord 2010; 25(2):189-193.

(155) Robb K. Psychological Aspects of Female Urinary Incontinence. Ulster Gynae Urology Society. 2006. 2006.
Ref Type: Unpublished Work

(156) The Cochrane Collaboration. The Cochrane Collaboration. http://www cochrane org/index htm [2010 Available from: URL:http://www.cochrane.org/index.htm

(157) Centre for Reviews and Dissemination. Centre for Reviews and Dissemination. http://www york ac uk/inst/crd/index htm [2010 Available from: URL:http://www.york.ac.uk/inst/crd/index.htm

(158) Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today 2004; 24(2):105-112.

(159) Newell R, Burnard P. A Pragmatic Approach to Qualitative Data Analysis. Vital notes for nurses: Research for evidence-based practice. Wiley-Blackwell; 2006. 97-107.

(160) Grimby A, Milsom I, Molander U, Wiklund I, Ekelund P. The influence of urinary incontinence on the quality of life of elderly women. Age Ageing 1993; 22(2):82-89.

(161) Harris A. Impact of urinary incontinence on the quality of life of women. Br J Nurs 1999; 8(6):375-380.

(162) Krause C, Wells T, Hughes S, Brink C, Mayer R. Incontinence in women: effect of expectancy to regain control and severity of symptoms on treatment outcomes. Urol Nurs 2003; 23(1):54-61.

(163) Ader R, Cohen N, Felten D. Psychoneuroimmunology: interactions between the nervous system and the immune system. Lancet 1995; 345(8942):99-103.

(164) Montoro J, Mullol J, Jauregui I, Davila I, Ferrer M, Bartra J et al. Stress and allergy. J Investig Allergol Clin Immunol 2009; 19 Suppl 1:40-47.

(165) Nunes-Costa RA, Lamela DJ, Figueiredo BF. Psychosocial adjustment and physical health in children of divorce. J Pediatr (Rio J) 2009; 85(5):385-396.

(166) Zachariae R. Psychoneuroimmunology: a bio-psycho-social approach to health and disease. Scand J Psychol 2009; 50(6):645-651.

(167) Segerstrom SC, Miller GE. Psychological stress and the human immune system: a meta-analytic study of 30 years of inquiry. Psychol Bull 2004; 130(4):601-630.

(168) Menninger KA. Some observations on the psychological factors in urination and genitourinary afflictions. Psychoanal Rev 1941; 28:117-129.

(169) Yazmajian R V. Pathological Urination and weeping. Psychoan Quarterly 1966; 35:40-46.

(170) Wyman JF. The psychiatric and emotional impact of female pelvic floor dysfunction. Curr Opin Obstet Gynecol 1994; 6(4):336-339.

(171) Molinski H. Masked depressions in obstetrics and gynecology. Psychother Psychosom 1979; 31(1-4):283-287.

(172) STRAUB LR, RIPLEY HS, WOLF S. Disturbances of bladder function associated with emotional states. J Am Med Assoc 1949; 141(16):1139-1143.

(173) Hammelstein P, Soifer S. Is "shy bladder syndrome" (paruresis) correctly classified as social phobia? J Anxiety Disord 2006; 20(3):296-311.

(174) Loriente ZC. [What is paruresis or shy bladder syndrome? A transdisciplinary research]. Actas Urol Esp 2007; 31(4):328-337.

(175) Soifer S, Nicaise G, Chancellor M, Gordon D. Paruresis or shy bladder syndrome: an unknown urologic malady? Urol Nurs 2009; 29(2):87-93.

(176) Middlemist RD, Knowles ES, Matter CF. Personal space invasions in the lavatory: suggestive evidence for arousal. J Pers Soc Psychol 1976; 33(5):541-546.

(177) Rees DL, Farhoumand N. Psychiatric aspects of recurrent cystitis in women. Br J Urol 1977; 49(7):651-658.

(178) Stone CB, Judd GE. Psychogenic aspects of urinary incontinence in women. Clin Obstet Gynecol 1978; 21(3):807-815.

(179) Walters MD, Taylor S, Schoenfeld LS. Psychosexual study of women with detrusor instability. Obstet Gynecol 1990; 75(1):22-26.

(180) Heidrich SM, Wells TJ. Effects of urinary incontinence: psychological well-being and distress in older community-dwelling women. J Gerontol Nurs 2004; 30(5):47-54.

(181) Carson CC, III, Osborne D, Segura JW. Psychologic characteristics of patients with female urethral syndrome. J Clin Psychol 1979; 35(2):312-313.

(182) Lagro-Janssen AL, Debruyne FM, Van WC. Psychological aspects of female urinary incontinence in general practice. Br J Urol 1992; 70(5):499-502.

(183) Berglund AL, Eisemann M, Lalos O. Personality characteristics of stress incontinent women: a pilot study. J Psychosom Obstet Gynaecol 1994; 15(3):165-170.

(184) Drutz H P. The role of psychological screening tests in the evaluation of women with persistent lower urinary tract problems: A prospective, blinded study. Urogynaecologia International Journal 1995; 9(1):21-30.

(185) Chiara G, Piccioni V, Perino M, Ohlmeier U, Fassino S, Leombruni P. Psychological investigation in female patients suffering from urinary incontinence. Int Urogynecol J Pelvic Floor Dysfunct 1998; 9(2):73-77.

(186) Bodden-Heidrich R, Beckmann MW, Libera B, Rechenberger I, Bender HG. Psychosomatic aspects of urinary incontinence. Arch Gynecol Obstet 1999; 262(3-4):151-158.

(187) Lin SY, Dougherty MC. Incontinence impact, symptom distress and treatment-seeking behavior in women with involuntary urine loss in Southern Taiwan. Int J Nurs Stud 2003; 40(3):227-234.

(188) Talbot LA. Coping with urinary incontinence: development and testing of a scale. Nurs Diagn 1994; 5(3):127-132.

(189) Griffiths F, Pepper J, Jorstad-Stein EC, Smith JF, Hill L, Lamb SS. Group versus individual sessions delivered by a physiotherapist for female urinary incontinence: an interview study with women attending group sessions nested within a randomised controlled trial. BMC Womens Health 2009; 9:25.

(190) Ghoniem GE, Stanford GE, Kenton K, Achtari C, Goldberg R. Evaluation and outcome measures in the treatment of female urinary stress incontinence:

International Urogynecological Association (IUGA) guidelines for research and clinical practice. Int Urogynecol J Pelvic Floor Dysfunct 2008; 19(1):5-33.

(191) Obrink A, Fedor-Freybergh P, Hjelmkvist M, Bunne G. Mental factors influencing recurrence of stress incontinence. Acta Obstet Gynecol Scand 1979; 58(1):91-94.

(192) Rosenzweig BA, Hischke D, Thomas S, Nelson AL, Bhatia NN. Stress incontinence in women. Psychological status before and after treatment. J Reprod Med 1991; 36(12):835-838.

(193) Department of Health. Department of Health (2000) *The NHS Plan*: *A plan for investment, a plan for reform*. 2000. London.
Ref Type: Report

(194) Department of Health. *Essence of Care*, London, Department of Health, 2001. 2001. London.
Ref Type: Report

(195) Department of Health. *National Service Framework for Older People,* Department of Health, 2001. 2001.
Ref Type: Report

(196) Hicks C. Repertory grid analysis. In: McCubbin M, Black S, editors. Research methods for clinical therapists. 5th ed. Churchill Livingstone Elsevier; 2009. 275-285.

(197) Toozs-Hobson P, Loane K. The psychology of incontinence. Why successful treatments fail. Margie Polden Memorial lecture. Association of Chartered Physriotherapists in Women's Health 2008;(102).

(198) Huisman S, Maes S, De G, V, Chatrou M, Haak HR. Low Goal Ownership Predicts Drop-out from a Weight Intervention Study in Overweight Patients with Type 2 Diabetes. Int J Behav Med 2009.

(199) Stratford PW, Binkley FM, Riddle DL. Health status measures: strategies and analytic methods for assessing change scores. Phys Ther 1996; 76(10):1109-1123.

(200) Ware JE, Jr., Brook RH, Davies AR, Lohr KN. Choosing measures of health status for individuals in general populations. Am J Public Health 1981; 71(6):620-625.

(201) Pal DK. Quality of life assessment in children: a review of conceptual and methodological issues in multidimensional health status measures. J Epidemiol Community Health 1996; 50(4):391-396.

(202) Zabora J R. Screening Procedures for Psychosocial Distress. In: Holland J, editor. Psycho-oncology. Oxford Uni Press; 1998. 653-661.

(203) Senf B, Brandt H, Dignass A, Kleinschmidt R, Kaiser J. Psychosocial distress in acute cancer patients assessed with an expert rating scale. Support Care Cancer 2010.

(204) Jacobsen PB. Screening for psychological distress in cancer patients: challenges and opportunities. J Clin Oncol 2007; 25(29):4526-4527.

(205) Girgis A, Breen S, Stacey F, Lecathelinais C. Impact of two supportive care interventions on anxiety, depression, quality of life, and unmet needs in patients with nonlocalized breast and colorectal cancers. J Clin Oncol 2009; 27(36):6180-6190.

(206) Akizuki N, Akechi T, Nakanishi T, Yoshikawa E, Okamura M, Nakano T et al. Development of a brief screening interview for adjustment disorders and major depression in patients with cancer. Cancer 2003; 97(10):2605-2613.

(207) Linden W, Yi D, Barroetavena MC, MacKenzie R, Doll R. Development and validation of a psychosocial screening instrument for cancer. Health Qual Life Outcomes 2005; 3:54.

(208) Snaith RP. The Hospital Anxiety And Depression Scale. Health Qual Life Outcomes 2003; 1:29.

(209) Lemyre L, Lalande-Markon MP. Psychological Stress Measure (PSM-9): integration of an evidence-based approach to assessment, monitoring, and evaluation of stress in physical therapy practice. Physiother Theory Pract 2009; 25(5-6):453-462.

(210) Podmore EJ, Bingham LC, Roberts KM, Selby PJ, Wright P, Velikova G. Routine assessment of social difficulties in cancer patients: are we opening Pandora's box? Support Care Cancer 2009; 17(11):1425-1432.

(211) Vittengl JR, Clark LA, Jarrett RB. Deterioration in psychosocial functioning predicts relapse/recurrence after cognitive therapy for depression. J Affect Disord 2009; 112(1-3):135-143.

(212) Gao F, Luo N, Thumboo J, Fones C, Li SC, Cheung YB. Does the 12-item General Health Questionnaire contain multiple factors and do we need them? Health Qual Life Outcomes 2004; 2:63.

(213) Hystad SW, Eid J, Johnsen BH, Laberg JC, Thomas BP. Psychometric properties of the revised Norwegian dispositional resilience (hardiness) scale. Scand J Psychol 2009.

(214) UK National Screening Committee. 2008.
Ref Type: Internet Communication

(215) Hewison J. Psychological aspects of integrated testing. BJOG 2004; 111(6):519-520.

(216) Magruder KM, Norquist GS, Feil MB, Kopans B, Jacobs D. Who comes to a voluntary depression screening program? Am J Psychiatry 1995; 152(11):1615-1622.

(217) Fleming SL, Pagliari C, Churchill R, Shuldham CM, McKean M. Psychotherapeutic interventions for adults with asthma. Cochrane Database Syst Rev 2004;(1):CD002982.

(218) Gambling T, Long A. Tailoring advice and optimizing response: a case study of a telephone-based support for patients with type 2 diabetes. Fam Pract 2009.

(219) Trower P CA, Dryden W. Cognitive-behaviour counselling in action. Sage Publications Ltd, London; 2004.

(220) Hicks C. Research Methods for Clinical Therapists. fifth ed. Churchill Livingstone Elsevier; 2009.

(221) Parahoo K. Nursing Research. 1st ed. Suffolk: Macmillan; 1997.

(222) Jane Ogden. Health Psychology. 3rd ed. Open University Press; 2004.

(223) Harris A. Impact of urinary incontinence on the quality of life of women. Br J Nurs 1999; 8(6):375-380.